EXPLORING THE PSYCHOLOGICAL EXPERIENCES AND RESILIENCY PRACTICES OF NAVAJO MOTHERS WHO GIVE BIRTH TO AND CARE FOR A PREMATURE INFANT IN A RURAL-SERVING NEONATAL INTENSIVE CARE UNIT

By Chelsey Lynn Tarazi

A Dissertation
Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
in Combined Counseling/School Psychology

Northern Arizona University
August 2021

Approved:
Yolanda E. Garcia, Ph.D., Chair
Katherine Feather, Ph.D.
Karen Applequist, Ph.D.
Maureen Russell, Ph.D.
Lisa L. Persinger, Ph.D.

ABSTRACT

EXPLORING THE PSYCHOLOGICAL EXPERIENCES AND RESILIENCY PRACTICES OF NAVAJO MOTHERS WHO GIVE BIRTH TO AND CARE FOR A PREMATURE INFANT IN A RURAL-SERVING NEONATAL INTENSIVE CARE UNIT

CHELSEY LYNN TARAZI

According to recent statistics, Indigenous mothers have one of the highest percentages of preterm births in the U.S. when compared to white mothers (Sparks et al., 2005). During 2011 to 2013, the premature birth rate in Arizona for Indigenous mothers was 14.2% compared to 10.6% for white mothers (March of Dimes, 2015). Yet, little research exists about the experiences of Indigenous mothers of premature infants in the NICU environment. For Navajo mothers, the rurality of many family homes, combined with cultural differences between mothers and hospital staff, create potential barriers to mother-infant bonding and the learning that must take place for mothers to care for infants once the infants graduate from the NICU. The purpose of this study was to explore Navajo mothers' lived experiences before and after the birth of their premature infants, and while their premature infants are cared for in a rural-serving medical center NICU in the Southwestern U.S. To explore Navajo mothers' lived experiences, three individuals separately participated in a demographics survey and an hour-long semi-structured interview conducted virtually. The use of Interpretive Phenomenological Analysis (IPA) for all three transcripts resulted in the emergence of three super-ordinate themes with subsequent sub-themes. Results revealed that resiliency during the perinatal period was salient for all three mothers, in particular the practice of cultural resiliency through traditional methods. Furthermore, the results highlight the need for individualized and culturally responsive treatment for Navajo and

Indigenous mothers who visit and care for their high-risk or preterm infants in traditional Western healthcare settings.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1

INTRODUCTION

Background

Despite efforts to increase the use of technology and to implement research findings into the Neonatal Intensive Care Unit (NICU) setting, each year at least 250,000 infants are born prematurely and at high risk. Although morbidity is decreasing due to better training and care in NICUs, premature infants continue to be at risk for developmental and neurodevelopmental disabilities and other health comorbidities (Enke et al., 2017). Along with concerns about their premature infants, families encounter emotional and financial burdens because of high-risk births (Melnyk., Alpert-Gillis, Feinstein, Fairbanks, Schultz-Czarniak, Hust, & Bender, 2001). The causes of premature birth have not been completely identified and involve both health and social factors. Current theories include maternal infectious diseases, intrauterine infection, maternal or fetal complications and other subclinical etiologies (Enke et al., 2017; Shapiro-Mendoza, 2016).

Due to uncertainty and lack of control regarding the neonate (i.e., infant’s health, maternal stress, etc.) in the NICU setting, mothers of preterm infants are often at an increased risk for anxiety, depression, and intense stress (Enke et al., 2017). Due to advanced technology, unfamiliar terminology, and urgency regarding infant care in the NICU environment, mothers often have difficulty relating to and attaching to their infants. A strong mother-infant relationship is a necessary foundation for strong early childhood cognitive and behavioral development (Als et al., 1994). Due to lack of knowledge and understanding, mothers may interact with their infants at inappropriate times (i.e., when infant is sleeping, when staff need to provide necessary medical care for the infants, etc.), leading to overstimulation for the infant and potentially negative effects (i.e., lack of response to intervention, illness, etc.; Mazurek-Melnyk et al., 2001).

Within the NICU setting, mothers are learning at-risk neonatal care from nurses. Although technological advances and science in the NICU are often crucial for infant survival, technological devices may negatively impact a mother's ability to interact and build relationships with their infant (Johnson, 2008) by serving as a barrier between the mother and child. For example, a mother being unable to interact with their infant due to a neonate needing to be in an incubator.

Although healthcare professionals in the NICU are trained to properly interact with and support families in this setting, open communication and interaction between staff and mothers continues to be difficult to navigate (Johnson, 2008). In a study addressing practitioner-parent communication in the NICU, at least 36% of parents could not identify a person on the NICU staff with whom they could talk and at least 25% felt they could not ask too many questions (Reid et al., 2007). In terms of mothers' needs, 90% of mothers in the NICU indicated that proper infant-related knowledge was their number-one need and that communication from the nurses regarding their infants' care and well-being was highly valued (Johnson, 2008).

Concerns and maternal stress due to caring for a premature infant and navigating communication between providers and families are challenges for mothers in the NICU. However, very little research has been published regarding the experiences of culturally diverse mothers caring for at-risk infants with little research to identify experiences of Indigenous mothers. Three studies addressing a majority (greater than or equal to 40% of participants) Non-Hispanic White mothers' experiences in the NICU found that these mothers experience high rates of psychological and psychosocial symptoms (i.e., stress, anxiety, depression, PTSD) when caring for their infant in the NICU (Lotterman, Lorenz, & Bonanno, 2019; Verbiest, McClain, Stuebe, & Menard, 2016; Welch et al., 2014). Brookes et al. (2016), conducted a longitudinal qualitative study on the experiences of Lumbee mothers in a North Carolina NICU within a cultural context and found that Indigenous mothers have similar experiences to the studies highlighted above, but may require more cultural understanding from providers. Brookes and their colleagues found that specific aspects of Lumbee culture were important for mothers when birthing and taking care of their premature infants. Important cultural aspects included care for the infants across multiple generations of women, practicing both traditional and nontraditional medicine, and taking pride in Lumbee heritage and culture. Brooks and colleagues (2016) urged NICU health care providers to learn how to deliver culturally appropriate services to better serve Indigenous families.

Findings of Brookes et al. (2016) highlight the need for incorporation of Indigenous cultures and perspectives when interacting with families of premature infants in the NICU. The study provides an impetus for learning about the needs of mothers with premature infants from other tribal cultures.

Statement of the Problem

The Navajo Nation in Arizona is the largest of tribal lands in the United States. Much of the land is remote with long drives to reach hospitals with neonatal units. Rurality of many family homes combined with cultural differences between mothers and most hospital staff create potential barriers to mother-infant bonding and the learning that must take place for mothers to effectively care for infants once they are released.

According to recent statistics, Indigenous mothers have one of the highest percentages of preterm births in the U.S. when compared to white mothers (Sparks et al., 2005). During 2011 to 2013, the premature birth rate in Arizona for Indigenous mothers was 14.2% compared to 10.6%

for white mothers (March of Dimes, 2015). Yet, little is known about the experiences of Indigenous mothers of premature infants in the NICU environment.

Before specific interventions or recommendations can be developed for health care providers and service delivery, information is needed regarding Navajo mothers' experiences in the NICU. Health disparities of culturally diverse mothers and their preterm infants are well-documented. These include disproportionate rates of infant prematurity and mortality, various cancers, cardiovascular disease, diabetes, HIV, and lack of access to necessary immunizations (Weber & Para-Medina, 2003), but there is not specific research to inform understanding of barriers, needs, and coping from the perspective of Indigenous mothers. does not exist.

The purpose of this study is to explore and understand Navajo mothers' challenges and experiences before and after the birth of their premature infants, while their premature infants are cared for in a rural serving medical center NICU in the Southwestern U.S., with the goal of informing the design of culturally competent care and services for Navajo mothers.

Conceptual Framework

This dissertation study is grounded in a health psychology and public health psychology theoretical framework and Tribal Critical Race Theory (Brayboy, 2006), as understood through the eco-social model of resilience (Ungar, 2012).

Gurung (2019) places health psychology into three categories: "stress and coping, health behaviors, and issues in health care" (p. 22). Public health psychology is closely tied with the foundations of health psychology but integrates public health and health promotion. Public health psychology is built on the concept that health can be impacted by research, environment, politics, and socio-economic status (Hepworth, 2004). Public health psychology is an adequate framework for this study, as it addresses the well-being and health behaviors of Navajo women, while also considering any potential barriers that may relate to the lack of research, the environment of healthcare systems, systemic oppression, and poverty.

Tribal Critical Race Theory (Brayboy, 2006), or TribalCrit, was developed from Critical Race Theory (CRT) to inform and provide a lens for issues that are uniquely related to and directly impacting Indigenous people in the United States. Critical Race Theory was originally discussed and coined by Kimberlé Crenshaw in the 1970's within legal studies to address the impact of racism and power in the legal system. The term now applies to a multitude of fields and phenomena, and other founders of CRT including Richard Delgado, Jean Stefancic, Gloria Ladson-Billings, and William Tate, posit that stories and individual narratives inform the known reality, and the use of stories as forms of knowledge often give voices to people of color (Delgado & Stefancic, 2017; Ladson-Billings & Tate, 1995). TribalCrit (Brayboy, 2006) is embedded in common "epistemologies and ontologies found in Indigenous communities," (p. 427) while also embracing the differences within these communities and the individuals within them. TribalCrit posits that Indigenous peoples' stories are data that inform others of how Indigenous communities function, and that "Stories are not separate from theory; they make up theory and are, therefore, real and legitimate sources of data and ways of being" (Brayboy, 2006; p. 430).

Ungar's (2012) social ecological model of resilience is a framework to view an individual or community's adverse experiences, that challenges traditional forms of resilience by addressing an individual or community's culture and the contexts in which people live. The model is in a sense, "heterogenous," as it is able to more accurately identify processes associated with resilience that are uniquely influenced by one's culture and the diversity of individual contexts, rather than utilizing a more "homogenous" definition that may not identify or capture such phenomena (Ungar, 2021; p. 387). Furthermore, Ungar's (2012) social ecological model of resilience highlights the need to identify resilience processes of individuals and communities that may be hidden due to white, Western constructs that often have a limited view of what resilience should look like. Due to this, it can be helpful when addressing diverse mothers' experiences. The model allows for resiliency to be viewed and analyzed in a cultural context, while also acknowledging the intersection of concepts that impact well-being, such as poverty or intergenerational trauma, and how those concepts may individually or collectively inform different types of resiliency.

This study aims to utilize health and public health psychology theory, Tribal Critical Race Theory (Brayboy, 2006) and a social ecological model of resilience (Ungar, 2012) to understand how culture and systemic barriers impact Navajo mothers' experiences in the NICU and when caring for their preterm infants. These theories were chosen for this dissertation study to highlight the intersection of health, resilience and culturally grounded storytellingstorytelling when considering effective health promotion and intervention for underserved populations such as Indigenous mothers and neonates.

Purpose of the Study

The purpose of this dissertation study is to conduct exploratory interviews with Navajo mothers to learn about their perinatal experiences when caring for their premature infants in a NICU setting. Due to the lack of research within this area of maternal and child health, this dissertation study is meant to inform current literature on Indigenous mothers' perinatal experiences in the context of prematurity and health interventions, and to inform future public health policy implementation and development.

Research Questions

This study aims to explore Navajo mothers' perinatal experiences prior to the NICU, their experiences in the NICU, and their experiences when preterm infants. Therefore, this study's goal will be to describe and represent the experiences reported by Navajo mothers who have given birth to a premature infant in a rural context. The mothers' experiences will be investigated via semi-structured interviews. This data will be used to answer the following research questions:

R1: How do Navajo mothers describe their perinatal experiences, including pregnancy and giving birth, while living in rural communities and when in medical facilities?

R2: How do Navajo mothers describe their postnatal experiences with their premature infant while they are cared for in a rural-serving neonatal intensive care unit?

Definition of Terms

Prenatal: before birth; during or related to pregnancy (Dictionary, 1989)

Perinatal: relating to the time, immediately before or after birth (Dictionary, 1989)

Postnatal: relating to the time period after childbirth (Dictionary, 1989)

Neonatal intensive care unit (NICU): A nursery in the hospital that provides 24-hour care for ill or premature infants (March of Dimes, 2015)

Premature infant: An infant born before 37 weeks gestation (March of Dimes, 2015)

Developmental NICU care: Medical interventions utilized in the NICU to reduce neonate stress to environment and to enhance neurobehavioral development (Sizun & Westrup, 2004)

Blessingway Ceremony: a Navajo rite-of-passage ceremony into motherhood (Begay, 2004)

Sing: A sing, or chant, is often used in Navajo ceremonies or rites, and focus on curing or gathering together (Begay, 2004)

Diné: Navajo individuals call themselves Diné, or “the people” (Navajo Tourism Department, 2019)

Rurality: a place-based sense of culture and heritage shared by a group of people, in a location that is deemed to be rural (Chigbu, 2013)

Poverty: living below the poverty line and therefore, making it difficult to provide for everyday life (World Bank, 2019). The poverty guidelines in the United States are published by the Department of Health and Human Services each year to help determine eligibility for federal assistance programs (U.S. Department of Health and Human Services, 2020).

Neonatology: the branch of medicine concerned with the treatment and care of newborn babies (March of Dimes, 2015)

Procedures

The dissertation study was a purely exploratory study that involved qualitative methodology while functioning from a constructivist framework. Along with pertinent demographic information collected (i.e., information regarding education, household income, etc.), semi-structured interviews were conducted with three participants directly recruited from health care entities and organizations that refer to or receive referrals from the medical center special care nursery. Specific inclusion criteria are discussed in further detail in chapter three. Mothers will be given Walmart gift cards as financial honoraria for their time. After interview data is collected, Interpretive Phenomenological Analysis (IPA) (Smith et al., 1999) will be used to find emerging themes and interpretive information within the mothers' responses about their experiences.

Significance of Study

There is a lack of research regarding Indigenous mothers' experiences of giving birth to and caring for premature infants. Due to the lack of research regarding Navajo mothers' practices and experiences while caring for a premature infant in a NICU, this dissertation study will add to the knowledge of neonatology and public health regarding equitable health intervention and promotion. To deliver supportive interventions and quality care for Indigenous mothers, and to develop and implement helpful public health policy that addresses disparities, a clear understanding is needed of Indigenous mothers' experiences and challenges within this setting.

Limitations of Study

Due to conducting research with participants from the Flagstaff Medical Center Special Care Nursery, the researcher will only have qualitative data to describe the experiences of Navajo mothers in this specific context and location. Furthermore, the study was conducted during COVID-19, and the mothers' communities were significantly impacted by the pandemic. This led to necessary changes in the methodology, specifically recruitment. Due to the limited internet and cellular service of one participant, her narrative was substantially more limited in nature and her story could not be recorded or analyzed for emotional or linguistic features. Additionally, the challenges associated with cross-cultural research can create limitations within the analysis and results. These challenges include making sure participants feel safe and respected during the interview, and ensuring that interview questions and subsequent analysis and results are both equitable and accurate reflections of the participants' narratives.

Organization of Study

The dissertation study will be organized into the following chapters: Chapter Two-Review of the Literature, Chapter Three-Methodology, Chapter Four-Results, Chapter Five-Discussion, and Chapter 6-Conclusion. Appendices following these chapters will include the demographics survey, the semi-structured interview, and necessary consent forms.

CHAPTER 2

REVIEW OF THE LITERATURE

The current study explored the experiences that Navajo mothers face when giving birth to a premature infant, and ultimately caring for the infant in a rural-serving Neonatal Intensive Care Unit (NICU). Within this section, published research along with general information in the following areas was addressed: (1) a description of the Northern Arizona region and the Navajo Nation, (2) historical trauma, (3)poverty and rurality in the Southwest, (4) Flagstaff Medical Center and the Special Care Nursery, (5) overview of the NICU and developmental NICU practices, (6) literature about mothers navigating the NICU environment, (7) mothers' interactions with NICU staff, (8) mothers' coping and resiliency skills in the NICU environment, (9) Navajo and Indigenous cultural practices with families and infants, and (10) social barriers underserved populations and Navajo mothers often encounter when receiving care and resources for their premature infants. Due to the limited amount of research documenting health disparities for Navajo mothers and their premature infants, reviewed studies of mothers from other various races and ethnicities regarding these issues help the reader inform how Navajo may perceive their perinatal experiences in the NICU environment.

Northern Arizona: Regional and Cultural Information

To better understand the context of the proposed study with Navajo mothers, it is important to understand the environment in which they live and raise children. While each of the three mothers in this dissertation study reside on the Navajo Nation, many Navajo families reside throughout the region of Northern Arizona.

Northern Arizona is a region defined colloquially within the state itself. It consists of Coconino, Mojave, Navajo, and Apache counties. It is also home to the Navajo and Hopi reservations, with the Navajo reservation being one of the largest tribal populations in the United States. Geographically, the entire area is on what is known as the Colorado Plateau, which hosts a plethora of both geographical and anthropological history for both Indigenous populations and settlers to the area. Northern Arizona is home to the Grand Canyon, the Painted Desert, and Monument Valley, all of which are popular tourist destinations and important landmarks in Indigenous history (Visit Arizona, 2019). Within Northern Arizona, Flagstaff is its largest city with a population of 71,975, followed by Prescott (population of 42,731), Sedona (population of 10,336), Page (population of 7,553), and Williams (population of 3,158). Flagstaff, an urban area in Coconino county, is home to Northern Arizona University and has a population of long-term residents and college students during the academic year. Within these cities, an intersection of culture and history exists for dominantly White, Hispanic, and Indigenous populations (Visit Arizona, 2019).

The Navajo Nation is a tribal region that spans 27,000 square miles within the Southwest, including the states of Arizona, New Mexico, and Utah. The Nation consists of approximately 155,000 Navajos, or Diné people, living within its borders, with at least 175,000 living in the surrounding border towns and regions (New Mexico Pregnancy Risk Assessment Monitoring System Data, 2011). Also known as Diné Bikeyah, or Navajoland, the Navajo Nation is larger than 10 of the 50 states in the U.S (Navajo Tourism Department, 2019).

The Navajo Nation is a vital and important cultural facet of the United States. The Nation may be most well-known for its rich and preserved language, Diné. From the homes of Navajos to government buildings, Diné is spoken and is an integral part of life on the Navajo Nation. (Navajo Tourism Department, 2019). In 2010, at least 51% of Navajo Nation citizens spoke Diné (Denetclaw, 2017). Spoken Diné and its complexity are of interest to many. This was especially so during World War II. Navajo Code Talkers, Navajo men who served in the U.S Army, primarily in the Pacific against Japan. They sent code in Diné, which the Japanese forces were never able to “crack” or decode (Navajo Tourism Department, 2019). Their service and bravery are a source of pride to the Navajo Nation and celebrated often.

Along with their rich history, the Navajo Nation is a cultural epicenter and thriving government and economy within the United States. In the early 1920’s, a tribal government was formed to address the economic impact of American oil companies after the discovery of oil in the region. Today, the Navajo Nation Council Chambers consists of 110 Navajo Nation Chapters, or regions, and is served by 88 council delegates. It is considered to be one of the most advanced and well-run Indigenous governments in the United States (Navajo Tourism Department, 2019).

The Navajo Nation flag depicts the values and everyday life of the Navajo people, and it can be used to better understand their history and culture. Created in 1968 by Jay R. Degroat, it depicts the outline of the Nation as it was described in the 1868 Treaty Reservation. On the North, South, East, and West points of the flag, the four sacred peaks are depicted. In the middle of the flag, the Navajo Nation symbol represents the tribe’s ability to continue to grow in a modern world while holding on to their language, history, and culture. The symbol includes sun rising over stalks of green corn, livestock to represent their livestock industry, a Hogan (traditional Navajo home) and a modern home, along with a modern sawmill to represent the Navajo Nation’s progress and industrial development (Navajo Tourism Department, 2019).

The Navajo Nation has made great strides to establish a wealth of cultural heritage and to strengthen its economic impact in the United States. However, like many other areas of the U.S. that are industrially and economically moving forward, poverty and its impact on people remains a challenge, especially in rural areas.

Historical Trauma

In the following literature review, instances of poverty, health inequities, and discrimination are discussed in-depth with Indigenous mothers as well as other mothers of culturally and linguistically diverse backgrounds. Before engaging in this information, it is crucial to address the concept of historical trauma and its relationship with health disparities, communities, and individuals (Goodkind et al., 2012). While many oppressed and underserved people have been impacted by historical trauma due to U.S. institutions of power, this section will discuss the concept of historical trauma and its negative impact on Indigenous communities in the United States.

Historical trauma is both psychological and emotional suffering that persists intergenerationally and for one's entire life (Brave Heart, 1998). Maria Yellow Horse Brave Heart, an expert and researcher in the concept of historical trauma, posited that while this trauma can be felt individually, it is a collective trauma that can be used to frame current health behaviors and responses to trauma (Brave Heart, 1998), rather than organizing Indigenous health outcomes into disparate labels and categories (Brave Heart, 1998; Farella, 1993).

Clinicians and researchers will frequently pathologize Indigenous communities without addressing the impact of historical trauma, and therefore Goodkind et al. (2012) discuss the concern of framing Indigenous health disparities as being perpetuated by the individual, indicating that researchers "…use behavioral health morbidity and mortality statistics that frame suicide and substance abuse as personal problems, which often lead researchers to emphasize individual interventions" (pg. 3). Therefore, it is important for researchers to recognize that historical trauma was inflicted on Indigenous communities, bodies, and minds through systematic oppression from social and political institutions of power over multiple generations;

and is therefore it is both collective, not individual, and a context through which health inequities must be viewed (Goodkind et al., 2012).

Goodkind et al. (2012) discuss the concept of historical trauma is often embraced and further conceptualized by Indigenous researchers and clinicians, as it represents and gives meaning to the destructive impact of hundreds of years of colonialism on Indigenous "individuals mental health and well-being" (pg. 6), while non-Indigenous individuals do not fully emphasize the intersection of historical trauma and suffering and current health disparities. Despite this, the following information in the literature review should be viewed through and understood through the concept of collective historical trauma and suffering. As Goodkind et al. (2012) suggested, "…the power of historical trauma as a concept is that it encourages the production of narratives about the relationship between current behavioral health inequities among many American Indian individuals, communities, tribes, and nations, and past and current oppressive policies perpetuated by the U.S. government, state governments, religious institutions and other institutions in the United States" (pg. 6).

Poverty and Rurality in the American Southwest

Poverty, while its definition continues to be changed, often refers to being economically disadvantaged. Whether this means living below the poverty line that exists within a country or lacking the ability to buy the things needed to survive in and contribute to an industrial economy (Akindola, 2009). The World Bank (2019), defines poverty as living below the poverty line and therefore, making individuals unable to provide for their everyday life. Poverty is not only defined as having low income but may also include one's physical location or isolation from society, vulnerability, level of self-respect, lack of information, or distrust for the state or government. Poverty affects the well-being of a nation's individuals, not just their economic security (Akindola, 2009).

Rural communities, according to the U.S. Census, are communities outside of main census areas with a population greater than or equal to 2,500, 10,000, or 50,000. Urban communities are defined as census areas with greater than 50,000 people (Cromartie & Parker, 2019). The definition of what is rural is commonly determined by comparing rural communities to urban communities. For instance, the distance the rural community is from an urban place, the size of the community, and the community's economy and sociocultural factors (Stern et al., 2010). In Arizona, the Arizona Census indicates that the rural counties in Northern Arizona include Mojave, Navajo, and Apache counties (Cromartie & Parker, 2019). Both Navajo and Apache counties are located within the Navajo Nation. It is important to differentiate between rural and rurality, as rurality can often explain behaviors or beliefs by a group of people. Rurality is a place-based sense of culture and heritage shared by a group of people, in a location that is deemed to be rural (Chigbu, 2013).

The Navajo people are impacted by the intersectionality of both poverty and rurality. According to the U.S. Census Bureau (2012), two out of the five most impoverished states in the U.S. are located on Reservations. The combination of being impoverished and living in a rural community can impact employment, education, and everyday life.

Indigenous populations in 2012 had the lowest employment rate out of any racial/ethnic group in the U.S. Between 2005 and 2011, Indigenous students were the only racial/ethnic group who did not have improved reading and math test scores and have the lowest high school graduation rates.

Family life and housing are greatly impacted by this intersectionality. Overcrowding in homes is three to six times higher than that of the U.S. as a whole, while at least 120,000 of Indigenous homes did not have basic water sanitation access in 2011, according to the Environment Protection Agency. The Indian Health Service reported that in 2011, 1 in 10 Indigenous homes lacked safe and clean water. Furthermore, at least 60% of Indian Reservation Roads are gravel or dirt, which can often be made inaccessible by adverse weather conditions (Running Strong, 2018).

On Reservations, internet and internet access is greatly impacted, and often more expensive than the rest of the United States. This creates a “digital divide” between rural and urban communities and may limit access to individuals and families living on Reservations (Running Strong, 2018).

The Impact of Poverty and Rurality on Indigenous Prenatal and Perinatal Health Outcomes

From 2005 to 2011, population surveillance data addressing health outcomes and behaviors of Navajo mothers before and after the birth of their child was collected in regions of New Mexico and Utah. This regional data collection is a part of the New Mexico Pregnancy Risk Assessment Monitoring System or PRAMS. Working in conjunction with the Center for Disease Control and Prevention (CDC), PRAMS addresses areas of need including prenatal care, counseling, multivitamin use, intimate partner abuse, teen pregnancy, home visiting, and unintended pregnancies.

Demographic and health outcome information that emerged from data collection were significant. From the 598 Navajo mothers who participated, majority of them were between 20 and 34 years of age, most were not married, and most had income levels below 185% of the federal poverty level (New Mexico Pregnancy Risk Assessment Monitoring System Data, 2011). Over half of the Navajo mothers who participated did not intend to become pregnant, with majority of these mothers being young and unmarried. 61% of participant mothers did not take multi or pre-natal vitamins prior to their child's birth, with at least 14% of mothers developing diabetes during pregnancy. Both a lack of pre-natal care and significant illness during pregnancy can lead to premature birth, neural tube defects, and overall poor birth outcomes (New Mexico Pregnancy Risk Assessment Monitoring System Data, 2011). Forty-three percent of Navajo mothers did not receive any prenatal care in the first trimester, and only half of Navajo mothers received adequate prenatal care.

In general, mothers with less education were less likely to access or receive prenatal care for their infants (New Mexico Pregnancy Risk Assessment Monitoring System Data, 2011). At least 20% of Navajo mothers indicated they experienced food insufficiency, with this being more likely for mothers with less education and higher poverty (New Mexico Pregnancy Risk Assessment Monitoring System Data, 2011). An emerging theme of this data is lack of resources, barriers to care, lack of education, and poverty among the Navajo maternal population. Another emerging theme was the lack of follow-up care and use of support and education programs by Navajo mothers. PRAMS investigators indicated this needed to be addressed with further data to understand why Navajo mothers are not utilizing these resources in higher numbers.

Rural Health Care: Northern Arizona Healthcare, Flagstaff Medical Center, the Special Care Nursery, and Indian Health Service

Northern Arizona Healthcare (NAH) is a network of hospitals, clinics, and specialties that serves the region of Northern Arizona. The network serves over 700,000 individuals across

50,000 square miles in majority rural areas. Within this network, Flagstaff Medical Center (FMC) is a hospital serving the Flagstaff area. FMC offers a variety of different specialties, including developmental pediatric clinics and neonatal care. Within FMC, the Special Care Nursery (SCN) is a specialty department that offers personalized treatment for premature and sick infants and their families. The SCN at FMC is considered a neonatal intensive care unit, or NICU. The nursery includes family rooms, family rounds, and parent education and resources. The SCN staff includes a neonatologist, neonatal nurse practitioners, a pediatric cardiologist, a perinatal social worker, and developmental specialists (Northern Arizona Healthcare, 2019).

The Indian Health Service (IHS) is a federal agency that delivers health care to a large percentage of the Indigenous population in the United States. Due to a variety of factors, including increased health disparities within the Indigenous population, lack of health care practitioners within rural areas and IHS facilities, and a shortage of funding, the quality of care and access of IHS services has been negatively impacted (Sequist, Cullen, Bernard, Shaykevich, Orav, & Ayanian, 2011). Furthermore, the only other NICU in the Northern Arizona region is housed within Tuba City Regional Health Care, and it is a Level II NICU, which cannot take all high-risk infants. Therefore, mothers who deliver their infants in Tuba City, Page, or Chinle, often transport their infants to the FMC Special Care Nursery, to receive more specialized care.

Overview of the Developmental Neonatal Intensive Care Unit

Over time, the goal of a neonatal intensive care unit (NICU) has changed from ensuring the survival of the pre-term infants to ensuring positive, long-term developmental outcomes. NICUs have also changed from being a crisis-oriented space to a space for mothers to gain confidence in being caregivers for their infants and a space to influence the mother-infant relationship (Als & Gilkerson, 1997). A developmental NICU encompasses interdisciplinary work between NICU staff that supports parent-infant relationships and the neurodevelopmental outcomes of neonates. This interdisciplinary team facilitates interactions between the infant, the parents, and the staff, to deliver family-centered care (Als & Gilkerson, 1997). Heidelise Als and her colleagues (1997) indicate that the underlying component of developmental NICU care is the relationships that exist within it.

More specifically, Als, Duffy, and McAnulty (1996) indicate the importance of neurodevelopmental outcomes of neonates, and how developmental care can inform these outcomes. Developmental NICU care teaches parents and caregivers how to recognize the neurological and emotional behaviors of their premature infants to best care for infants' strengths, needs, and growth. When NICU staff can help instill confidence in caregivers' abilities to find opportunities to react to and care for their neonate, the mother-infant relationship improves, along with the infants' neurodevelopmental outcomes (Als et al., 1994; Als et al., 1996). Mothers' interactions with NICU staff and their infant directly impact the mother-infant relationship.

Mothers Navigating the NICU Environment

When an infant is cared for in a Neonatal Intensive Care Unit (NICU), the mother of this infant faces a range of global and personal challenges, and many mothers feel unprepared for what lies ahead. Between the premature infant being admitted into the NICU and the infant graduating from the NICU, is a journey that requires the mother to adjust to a new environment, learn new terminology, and find support for herself and her baby (Vasquez & Cong, 2014). In a meta-ethnographic synthesis of literature comprised of 12 qualitative research studies and two nursing dissertations, conducted by Vasquez and Cong in 2014, the phenomenon of being a mother in the NICU was synthesized. According to their review, the environment in which a mother finds herself in is often facilitated, positively or negatively, by the nursing staff.

Ultimately, key factors that facilitate parenting in the NICU environment (Vasquez & Cong, 2014) are the mothers' ability to be in contact with and engage with their infants, maintain relationships with NICU staff, rely on social support, and gather all the information they need to understand their infants' situations. Before an infant can be discharged from the NICU, the mother must feel confident and competent in her abilities to care for her infant without staff support, and to begin her journey of knowing her infant outside of the NICU. Vasqeuz and Cong (2014) discerned that NICU nurses are the key players in facilitating mothers' growth and confidence while their child is in the NICU and after they leave. Navigating the NICU environment is a challenge for all mothers, but is particularly difficult for underserved mothers, including those from Black and Indigenous communities. Below, the review of current literature about navigating the NICU environment will address the climate of the NICU and its impact on maternal support, the connection between the NICU environment and the mother-infant relationship, and ways in which the NICU environment ultimately leads to NICU discharge and follow-up care.

NICU climate and support for mothers.

The first visit to the NICU is, at best overwhelming, surprising, and potentially frightening for a mother of a premature infant. Being "novices" within this environment, mothers have nothing to which they can compare this experience. Mothers may be wondering, "What are all of these machines for?", "What is that noise coming from my baby's incubator?", "Am I supposed to hold my baby a certain way?", "Are there rules in this NICU for visitation and family interactions?", and "What is wrong with my baby and what do abbreviations such as RSV stand for?” (Vasquez & Cong, 2014, pg. 283). All these questions address understanding terminology and understanding the hospital’s rules. Ultimately, a supportive NICU climate is necessary for mothers to begin this process.

In a qualitative study exploring mothers’ experiences in receiving counseling in a NICU, Parker (2010) found a series of themes within the mothers’ accounts. This small-scale study, like the current dissertation study, had six participants who delivered a premature infant who received care in a NICU. Within this sample, five of the mothers had never received counseling or perinatal support, compared to one mother who had received counseling support prior to the experience for almost five years. The authors contended this was representative of the NICU population, which typically consists of mothers with a wide range of experiences (Parker, 2010). After content analysis was conducted for each of the six interviews, multiple themes emerged from the study. The six mothers shared that the psychological impact of having a premature infant is not something for which they were prepared. The psychological impact included being in constant fear of their infants’ death, feeling as if they have no control over their own lives, and unpredictability (Parker, 2010). The mothers felt that the psychological impact could be reduced if they had known a parent going through a similar situation, as they often felt that they could not share their experiences with family and friends due to lack of understanding. The mothers reported that nurses were one of the best forms of support, but some interactions with nurses led to further stress.

Nurses within this study provided normalcy in an environment that was foreign to mothers. However, the mothers reported feeling as though their babies were ultimately in the hand of the nurses, and anything they said or did could cause a negative impact on how the nurses would treat their infant (Parker, 2010). Ultimately, the mothers felt supported and strengthened by receiving counseling in the NICU but indicated that counseling is also needed following NICU discharge, to continue to address parenting challenges (Parker, 2010). It is important to note that the author of this study did not report the ethnicity of the mothers who participated in the study, and therefore no conclusions can be drawn from this study to relate to culturally and linguistically diverse mothers who give birth to a premature infant.

Many experiences in the NICU, including its overwhelming environment, are universal to all mothers, but mothers of different ethnic backgrounds may experience an additional dimension of cultural barriers. In addition to lack of representation of underserved populations in NICU environment studies, disparities in care, and of infant mortality rates are key to understanding the NICU experience.

In a qualitative study conducted by Sigurdson, Morton, Mitchell, and Profit (2017), family advocates and NICU clinicians provided narrative accounts of disparities in quality of care for mothers with babies in the NICU. Physicians, nurse practitioners, and family advocates are included as participants for this study, with sample size of 324. The providers reported that disparities in quality of care for mothers of premature infants occurred due to language, race/ethnicity, and socio-economic status, as well as drug use, immigration status, and disability. The convenience sample of participants were required to complete a Qualtrics survey that allowed them to share an account of a racial/ethnic experience they have encountered in the NICU, along with the racial/ethnic background of the presumed patient they encountered. The responses were then coded to discover emerging themes in the narratives. Within the patient demographics, five of the mothers were Indigenous and 57 were white mothers. The participants' narratives described that 47% of disparities in the NICU environment were due to language, 30%

were due to culture/ethnicity, 22% were due to race, and 13% were due to socio-economic status of the mothers.

Twenty-six percent of the participants identified neglectful care, judgmental care, and systemic barriers to care. Participants described situations where they had witnessed certain families receiving more attention from practitioners than other families. These accounts included nurses who ignored families if they did not speak English, and nurses who did not utilize translators routinely or effectively. Participants described accounts of mothers and their families not receiving the same quality of care as other mothers due to their race, SES, or drug use. Participants described accounts in which they had witnessed NICU staff making fun of "Black sounding names", calling young fathers "baby daddy", and assuming volatile behaviors from Black families who were emotional when compared to the flexibility and understanding emotional white families were given (Sigurdson et al., 2017). Forty-four percent, almost half of the participants, attributed lack of quality care for mothers to systemic or social barriers. The participants indicated that these barriers caused parents to be less involved in the NICU and unable to do as NICU practitioners asked of them (i.e., daily care for infant, family time with infant) (Sigurdson et al., 2017). Although only 5 of the presumed patients in the participants accounts identified as Indigenous, the conclusions drawn from this study represent the experiences that culturally diverse mothers encounter when caring for their infant during and after the NICU, and in healthcare beyond.

While neonatal mortality fell dramatically from 28.8 deaths per 1000 in 1940 to 4.6 deaths per 1000 in 2000, infant mortality for culturally diverse families has increased over time. More than half of these deaths are due to infants being born with very low birth weight (VLBW); (Morales, Staiger, Horbar, Carpenter, Kenny, Geppert, & Rogowski, 2005). Morales et al.,

(2015) addressed mortality differences for culturally-linguistically diverse infants by examining a network of hospitals' patient volume, level of care, and differences when using effective treatments. The hospitals' data were tracked between the years 1995 and 2000. A total of 74, 050 Black and white infants were included in the study sample from the hospital network in the Northeastern region of the United States.

Overall, Black infants, compared to white infants, were born at a much earlier gestational age, weighed less, and had lower appearance, pulse, grimace, activity, and respiration (APGAR) scores. Black infants were less likely to be treated with antenatal steroids and surfactants during NICU care, and Black mothers were less likely to receive prenatal care compared to white mothers. Black infants were treated in mainly Black -serving hospitals, with 8% of Black infants being treated at hospitals which rarely served Black families. Black infants were more likely to be born in government run hospitals, hospitals with lower expenses per admission, and hospitals that served mainly Medicaid patients. The authors found that if a Black infant was born in a minority-serving institution compared to an institution where 15% or less of the infants were Black, the chances of infant mortality increased (Morales et al., 2015). The authors also found that certain factors, including level of education, poverty status and prenatal care also impacted Black infants' higher mortality rate compared to white infants.

The study suggests that culturally diverse families may already be facing factors that can impact infant mortality and quality of care, a situation that is exacerbated when mothers only have access to under-funded institutions (Morales et al., 2015). In a study completed in Canada regarding ethnic differences in neonatal infant mortality rates, 6528 infants were included in the sample, with 929 of those infants being Indigenous, or Indigenous if in the United States. Indigenous infants had a higher rate of infant mortality compared to white mothers, primarily due to Indigenous mothers' lack of access to prenatal care and residing in rural areas (Claydon, Sankaran, and Lee, 2007). As with the previous study, Indigenous mothers facing social barriers to care, along with higher mortality rates, can contribute to the vulnerability of mothers who are navigating a harmful NICU climate.

In a thesis study conducted by Minette Marcotte in 2017, a qualitative study, NICU health care providers in Canada were interviewed on their views of Indigenous mothers who give birth to an infant in a NICU, ultimately to inform the author on the NICU climate that Indigenous mothers experience. A total of 7 providers were given semi-structured interviews regarding their work in NICUs with Indigenous mothers. These providers included physicians, nurses, and social workers. The NICU environments included were both urban and rural. Interviews were coded utilizing content analysis and several themes emerged, including barriers, confusion about hospital policy, judgment, support/empowerment, oppression, and racism (Marcotte, 2017). Barriers mothers faced included limited access to prenatal care due to living in rural areas. However, the participants described this barrier as being only briefly noted in a mother's chart. The author noted that if a brief note is made, but communication is not facilitated, the mothers do not know when to provide more information regarding their own prenatal care and experiences. This creates confusion for the mother and a lack of communication between mothers and the NICU staff.

Marcotte (2017) indicated that nursing staff are often aware of barriers that exist for Indigenous mothers, as noted in their interviews. However, the staff do not move past the state of knowing into a state of action, which contributes to less support for the Indigenous mothers in the NICU environment. Within a climate that feels unsupportive, Indigenous mothers are not prone to ask about resources that are available to them, potentially out of fear of being seen as a bad mother (Marcotte, 2017). NICU staff reported in the interviews that they admitted to having passed judgment on Indigenous mothers and had also witnessed others doing so. The author indicated that this presence of judgment in the NICU also impacted decisions that nurses, and physicians made regarding the health of the mother and her premature infant. Judgment may contribute to NICU staff falsely assuming a child should not be with the mother due to a history of physical abuse or family violence on the mothers' accounts (Marcotte, 2017). An example of judgment from nursing staff could be related to how often a mother visits, or how much time a mother spends with her infant.

Overall, Marcotte (2017) found that NICU staff were engaging in actions and behaviors that created further barriers, by passing judgment, and engaging in both overt and inadvertent oppression and racism that created an unsafe climate for Indigenous mothers in the NICU.

NICU experiences for Indigenous women.

Although there is little research on the experiences of Indigenous women who give birth to premature infants, especially regarding Navajo women, a study conducted in North Carolina addressed giving birth to premature infants in a cultural context for women of the Lumbee tribe. The Lumbee people, who live in both urban and rural communities, originated in the Southeast area of the United States. The Lumbee tribe is recognized by the federal government but is still fighting for federal designation and federal benefits to this day (Lumbee FAQ's, 2019). Brooks, Holdtitch-Davis, Docherty, and Theodorou (2016), conducted a longitudinal qualitative study to explore Lumbee womens' perceptions of parenting and their NICU experience. Seventeen Lumbee mothers participated in semi-structured interviews over the course of three months, which were analyzed using content analysis. The results indicated that at three months, most of the mothers felt unprepared for an early birth, and many felt guilty they could not carry the infant full term. For many of the mothers, this guilt persisted up to almost a year after the birth. Lumbee mothers reported conflicting relationships with providers in the NICU. Some reported positive outcomes while others reported a lack of consistent communication and support. Some mothers reported being talked down to and felt frustrated when nurses could not correctly identify their ethnic background. Many of the mothers felt their efforts to be close with their infants were made worse by negative relationships and interactions with nursing staff (Brooks et al., 2016). The study highlighted cultural differences between Lumbee mothers and the nursing staff, which resulted in negative experiences for the mothers in the NICU. Although this study is focused on Lumbee women, Navajo women may be experiencing similar consequences to the intersection of their culture and Western NICU environments.

As described in these studies, mothers who give birth to premature infants feel a lack of control, confidence, support, and safety, which can at times, be either promoted or improved by NICU staff. Culturally and linguistically diverse mothers are also facing a lack of access to high-quality care, which can create environments that increase infant mortality rate.

Leslie Alimier (2015) outlined the introduction of a care-giving framework that can be utilized to improve quality of care for mothers and their premature infants. This framework, Compassionate Family Care Framework, infuses compassion into relationships with health care providers and provides parents with control and decision-making power, and attempts to foster positive identities of NICU mothers. The literature described above considers the NICU environment, which can be a stressful and scary place for all mothers. However, disparities within these challenges can emerge for underserved populations, particularly for Black and Indigenous mothers. Alimier (2015) indicates that utilizing a framework built on compassion may create a safer and more supportive environment for mothers in the NICU, however, this author does not outline culturally competent care. While NICU staff can retain compassion, many cannot control their biases and judgements toward mothers from culturally and linguistically diverse backgrounds, ultimately creating further environmental challenges for the mother regarding the mother-infant relationship, NICU discharge, and follow-up care.

Mother-infant relationship.

From the literature described above, the NICU environment is a challenging place to navigate for all mothers, however culturally and linguistically diverse mothers have additional challenges compared to white mothers. One challenge that all mothers face is creating quality time with their infants while they are in the NICU. According to Sigurdson et al., (2017), one major challenge for culturally and linguistically diverse mothers is being able to get to the NICU to spend time with their infants. These challenges are often caused by social and systemic barriers such as lack of transportation, long distances to and from the hospital, or financial difficulties. Mothers may be unable to participate in activities such as Kangaroo Care, which involves skin-to-skin contact with their infant. According to Gonya and Nelin (2012), skin-to-skin contact, or the mother holding her baby, can reduce detrimental deficits associated with preterm birth, including cognitive and emotional deficits. It can also facilitate strong maternal-child bonds. However, many NICUs are finding this form of quality care difficult to implement for all mothers. In a qualitative study that took place in a Level III NICU in the Midwestern United States, 32 neonates and their mothers were studied. Mothers’ stress and communication between mothers and staff were measured. Ultimately, Gonya and Nelin (2012) found that two things can inhibit a mother’s ability to perform skin-to-skin contact with their infant: how much stress the mother is under and perceived quality of communication with NICU staff. The authors found that if the NICU environment and climate does not feel supportive or welcoming, mothers may find coming to visit their infants challenging. They may also find it difficult to initiate communication with the NICU staff regarding their infants' care (Gonya & Nelin, 2012).

Skin-to-skin contact is a challenging goal to achieve for all NICU mothers but may be particularly difficult for diverse mothers due to cultural and linguistic barriers to care. A NICU climate of culturally competent communication and care is key to underserved mothers. For Indigenous mothers in the rural Southwest in particular, additional barriers to spending time with their infants are often things outside of their control, including transportation over long distances to get to a hospital with a NICU and limited financial resources for gas and lodging. Trips to the NICU create logistical and financial stress marginalized families.

NICU discharge and follow-up care.

Graduating from the NICU is a very important step for both the premature infants and their mothers. However, this transition is often met with uncertainty and fear for the mother, as they continue to navigate the NICU experiences within their own homes. In a qualitative study of 25 parents, including 15 mothers from the Chicago area, were interviewed for what they saw as parental concerns during the transition from the NICU to home (Garfield, Lee, & Nam Kim, 2014). Semi-structured interviews were coded utilizing content and narrative analysis to find multiple emerging themes, including continued uncertainty from parents, continued medical concerns, and parent adjustment. The parents chosen and identified for the study sample were all English-speaking and 18 years of age or older and had given birth to a very low birth weight (VLBW) premature infant, or an infant weighing less than 1,500 grams. Sixteen percent of the parents interviewed were white, to 3% Black, 5% Hispanic, and 1% other (Garfield, Lee, & Nam Kim, 2014). In terms of continued uncertainty, mothers in the study expressed their fears of additional medical complications for their infants after they were discharged and feeling worried, they will make a mistake that would prove detrimental to their infants' health. Infants who are born VLBW continue to have feeding and weight-gain concerns, which contributes to continued urgency on the parents' account. Both mothers and fathers indicated their concern for being able to care for their infants. However, mothers identified lack of sleep and knowing how to care for a premature infant as major concerns. Fathers reported concerns about the mothers' well-being and ultimately being able to care for a premature infant when fathers are not at home (Garfield, Lee, & Nam Kim, 2014).

While majority of mothers in the previous study were white, in a study conducted by Miquel-Vargas, Donohue, and Boss (2010), discharge of premature infants from the NICU for Latino families with limited English proficiency was explored to assess families' needs. Thirty-six mothers were interviewed at discharge and one month later. Although there was not a control group within the study, results of the mothers interviewed were compared with a subset of results from English-speaking mothers from the same NICU. Thirty-nine percent of the Latino mothers had received an education up to 8th grade, 28% had no primary source of support inside the United States (i.e., family or partner support), and almost half of the mothers earned less than $10,000 annually (Miquel-Vargos, Donohue & Boss, 2010). The quantitative study results found that Latino mothers with limited English proficiency were more likely to state that NICU staff were friendly and available, however they did not feel comfortable asking questions and felt unable to make decisions regarding their baby when compared to English-speaking mothers. Only 15% of Latino mothers in the study could identify critical risk factors for their premature infant after discharge and less than half of the Latino mothers were aware of early intervention services available to their infant (Miquel-Vargos, Donohue & Boss, 2010).

The studies discussed above indicate that discharge from the NICU brings about concerns for all parents, but further challenges need to be addressed for culturally and linguistically diverse parents. Parents with limited English proficiency encounter challenges in relationships with NICU staff and the NICU climate that can jeopardize health outcomes for infants.

As identified in the previously mentioned study, follow-up care is a necessary component for the health of discharged infants, but not always clearly understood or utilized by mothers of infants discharged from the NICU, especially those who are typically underserved or who speak limited English. In a quantitative study completed in Nebraska, 5856 infants who were enrolled in state-based follow-up and early intervention services, were included in the overall sample. Eighty-two point one % of the participants were white, 33% of the infants were on Medicaid, and 26.8% of the infants resided in a rural area (Roberts, Krehbeil, & Jackson, 2016). After analysis of the descriptive statistics and comparing low-risk infants with high-risk infants regarding medical care, it was found that infants covered by Medicaid, infants who were considered low-risk, and infants culturally-linguistically diverse were the least likely to attend and complete follow-up services after NICU discharge (Roberts, Krehbeil, & Jackson, 2016).

The studies addressing discharge and follow-up care indicate that cultural and linguistic issues contribute to mothers understanding of the NICU environment and post-discharge care of their premature infants compared to white mothers. Not only does language have an impact on the NICU climate for a mother, but education, SES level, and awareness of resources have been identified as lingering difficulties after a NICU stay.

Summary.

The NICU environment is challenging yet pertinent to premature infant development. Mothers face multiple challenges to caring for their infants navigating the NICU environment.

These challenges include understanding terminology, understanding rules and guidelines that hospitals enforce, overcoming social and financial barriers to visit their infants, linguistic challenges, and ultimately leaving the NICU and caring for their infants at home. The studies described above are a mix of participants which include both white and culturally diverse mothers from underserved populations. These studies inform the current dissertation study about potential challenges of the NICU for diverse mothers and potential health disparities for premature infants.

Mothers' Relationships and Communication with NICU Staff

As discussed in the previous section, the climate of the NICU is vital to mothers' ability to gain the knowledge and skills required for the health of premature infants. NICU climate is influenced by staff, nurses, and hospital policies and procedures. Ultimately, positive relationships and healthy communication between mothers and NICU staff is a foundation for culturally competent and quality care for all mothers and their premature infants. Although healthcare professionals in the NICU are trained to properly interact with and support families in this setting, open communication and interaction between staff and mothers continues to be difficult to achieve (Johnson, 2008). Johnson (2008) found in a study addressing NICU parent-practitioner relationships, that 90% of mothers in the NICU indicated that proper infant-related knowledge was their number-one need, and that communication from the nurses was highly valued. In a study addressing practitioner-parent communication in the NICU via a rating scale, at least 36% of parents could not identify a person on the NICU staff with whom they could talk to and at least 25% felt they could not ask too many questions (Reid et al., 2007).

Both healthy and unhealthy communication between mothers and NICU staff can influence the perceptions that mothers have in the NICU. In a literature review conducted by

Tondi Harrison (2010) in the *Journal of Pediatric Nursing*, a call to action was described regarding family centered care in NICU settings. Thirty papers were reviewed by the author and divided into three sections: observations of parent and nurse interactions, the perspective of parents, and the perspective of health professionals. Parent-nurse interactions observed in the review indicated that nurses were experts while parents were merely "visitors" (p. 4). Other parent-nurse interactions revealed that nurses thought parents helped relieve them of some bathing and feeding, but that parents were not a part of the daily routine and were therefore left out of pertinent caretaking and planning needs for the premature infant.

In the review of observations, parents were also seen as "bystanders" at times, while the nurses appeared to take responsibility for the infants' care without including the mothers (p.4). The author of the review concluded that these relationship routines within the NICU environment create further challenges for the mother. When interactions between nurses and mothers are primarily to provide information regarding infants' status, mothers cannot be supported to develop relationships with their infants and eventually take over primary caregiving roles (Harrison, 2010). Harrison (2010), found in a review of a NICU studies, that even when mothers actively worked to develop relationships with health care professionals, mothers had to overcome multiple barriers to assume a position of authority when caring for their infants. These barriers included a lack of staff which limited the amount of time nursing staff could communicate with the mothers, assignment of multiple staff members to care for the infant, which did not allow for mothers to creating lasting relationships with even one staff member, and concerns that numerous attempts to build rapport with the NICU staff would negatively impact the care their infants received. Mothers in this NICU study also found that attempts to try and communicate with some NICU staff were seen as questioning the staffs' competence (Harrison, 2010).

In a mixed-methods study conducted by Lilo, Shaw, Corcoran, Storfer-Isser, and Horwitz (2016), 56 Spanish and English-speaking mothers participated in semi-structured interviews regarding their perceptions of their NICU experience. After the interviews were transcribed and analyzed using content analysis and statistical analysis, several themes emerged in the data. Mothers with higher levels of education and higher household income made positive comments regarding emotional support from NICU staff. This was 2.5 times higher than mothers with less education (Lilo et al., 2016). Mothers in the study reported that to trust the NICU nurses, they felt they needed to bond with the nurses and get emotional support from them. Mothers indicated that NICU nurses did not always recognize how overwhelmed mothers were.

In terms of parent empowerment, mothers reported that being informed about what to expect with their premature infant helped instill control (Lilo et al., 2016). Mothers also indicated that when NICU staff were not available to discuss expectations with them, they felt angry or confused, and unable to understand their infants' situations. Mothers with less education reported more negative comments regarding the NICU being a welcoming environment and NICU policies as supporting their needs, when compared to college-educated mothers. On the other hand, less-educated mothers found themselves grateful for any form of parent training regarding their premature infant, while more educated mothers were more likely to make a negative comment regarding parent training (Lilo et al., 2016).

The author of the study also highlighted an important conclusion about ethnicity and education which was that non-Hispanic mothers with higher levels of education entered NICU environments *expecting* a certain level of support, while non-white, less educated mothers may be prone to feeling intimidated by NICU staff. While white mothers felt emotionally supported overall, Hispanic mothers reported a lack of nursing staff at their infants' bedside, staff being rough or curt, and infants being left unattended (Lilo et al., 2016). This study brings about important considerations for culturally competent care and educating NICU staff about diverse perspectives about parent training, supportive behaviors, and expectations influenced by ethnicity and level of education.

Culturally competent communication and relationships.

The relationships mothers form with NICU staff and nurses appear to be related to pre-determined factors regarding the mothers' ability to advocate for themselves, and their overall expectations of the NICU environment. In a study addressing culturally competent care for NICU staff, 21 culturally and linguistically diverse parents were interviewed in a Canadian NICU (Wiebe & Young, 2011). Six of these parents identified as being Indigenous. As an exploratory, qualitative study, the parents participated in semi-structure interviews analyzed using content analysis.

The following themes emerged from the data: relationships between healthcare providers and parents, communication, social/spiritual support, and the organization of the NICU environment (Wiebe & Young, 2011). Due to some of the parents' lack of expertise in medical care and terminology, they would rely on the nurses' interactions with their infant to determine quality care. If the nurse would interact warmly with the parents and infant, take time to explain information, and would respond quickly to a crying baby, the parents interpreted their actions as caring and trustworthy (Wiebe & Young, 2011).

However, out of all the parents, Indigenous parents reported more caution when developing relationships with NICU staff due to intergenerational and historical trauma of being discriminated against. Relationships are often “guarded and cautious” due to this history of maltreatment (p. 79). The author identified assignment of consistent and regular staff to care for Indigenous infants to overcome mistrust (Wiebe & Young, 2011). Indigenous parents were also more likely to seek spiritual supports and connections (i.e., spiritual resources or advice) from the NICU staff. For Indigenous mothers, health care is not only medical, but spiritual in nature, and the mothers in this study reported this was an important aspect to their relationship with NICU staff, especially if they were far from home (Wiebe & Young, 2011).

This study highlights that mothers who are culturally and linguistically diverse require different types of relationships with NICU staff compared to white mothers, and the importance of staff and nurses being culturally aware of all mothers’ needs including those that are spiritual.

In a study conducted by Birch, Ruttan, Muth, and Baydala (2009) in Alberta, Canada, culturally competent care for Indigenous women was analyzed. The authors of the study chose to address the need for culturally competent care as more Indigenous women choose to utilize urban hospitals to give birth to their infants. The authors noted that the lack of research about how to support these mothers creates challenges for health care providers in the field of maternal and child health. The authors argued that culturally competent care in this field requires neonatal and pediatric staff to engage in self-awareness and skill development. This can potentially be done by partnering with Indigenous providers, conducting community-based research, and educating staff about Indigenous practices and beliefs regarding maternal and child health (Birch et al., 2009).

Summary.

The studies reviewed in this section indicate a regard for how culture, education, and SES can impact the way parents perceive and receive support from NICU staff and nurses. Latter studies in this section identify a need for culturally competent care that will urge NICU staff to provide healthy and supportive relationships for all mothers. NICUs staff and nurses are encouraged to seek out training, and to learn and incorporate cultural practices and beliefs regarding motherhood and childcare held by diverse mothers.

Mothers' Coping and Resiliency in the NICU

Navigating the NICU environment, trying to establish trustworthy and caring relationships with NICU staff, and the healthcare needs of a premature infant can be an extremely stressful experience for all mothers, and particularly for culturally-linguistically diverse mothers (Shaw, Bernard, Storfer-Isser, Rhine & Horowitz, 2012). Mothers report a sense of emotional distress, including symptoms of anxiety and depression, sleep disorders, and even posttraumatic stress disorder (PTSD); (Shaw et al., 2012). A specific disorder associated with mothers who have an infant in the NICU is called acute stress disorder (ASD), for which a mother can begin to show symptoms very early in their premature infant's NICU stay. This disorder may be associated with later development of PTSD. There are several risk factors for mothers' inability to cope with the stress of the NICU, including, a history of psychological disorders, negative mother-staff relationships, and lack of control in the situation (Shaw, Bernard, Storfer-Isser & Horowitz, 2012). Parents who feel acute stress and lack of coping skills may feel inadequate and helpless in their pursuits to care for their premature infant (Shaw, Bernard, Storfer-Isser & Horowitz, 2012).

Mothers' coping skills in the NICU.

In a study addressing parental coping styles for mothers who have an infant in a NICU at Lucile Packard Children's Hospital at Stanford University, 56 mothers completed questionnaires regarding acute stress, trauma, and coping style. 56% of the mothers were white, 20% were

Hispanic, 20% were Asian, and 4% were identified as other race/ethnicity. Within this sample, 80% of Hispanic mothers reported high school or fewer years of education, compared to 4% of white mothers and 10% of Asian mothers with high school or fewer years of education (Shaw, Bernard, Storfer-Isser & Horowitz, 2012). The results indicated that mothers who were educated, white, or Asian, had significantly higher coping skills than mothers who were Hispanic or uneducated. Mothers who were married or partnered also had higher coping skills during the NICU stay than mothers who were single (Shaw, Bernard, Storfer-Isser & Horowitz, 2012). The study highlighted that mothers with less education and who are culturally and linguistically diverse, have more difficulty coping than white, educated mothers, which can create a disparity in culturally and linguistically diverse mothers' mental health during a NICU experience. Symptoms of perinatal depression and anxiety in culturally-linguistically diverse women will be discussed further in this section of the review.

Psychological distress for mothers parenting a premature infant.

In another study addressing the psychological impact of the NICU experience on mothers' coping and emotional distress, 91 mothers who had given birth to a moderate to late preterm infant (i.e., between 32 and no later than 36 weeks gestation) completed questionnaires rating their depression, anxiety, and PTSD symptoms. Majority of the mothers were white (40.7%), while 2.3% were Indigenous (Lotterman, Lorenz, & Bonanno, 2018). The mothers' psychological symptoms were assessed at the beginning of their premature infants' stay in the NICU and then six months later. Ultimately, most of the mothers had elevated symptoms of depression, anxiety, and PTSD after six months, indicating a need for support and psychological intervention for mothers who are currently active in the NICU, and beyond (Lotterman, Lorenz, & Bonanno, 2018). This study, along with the above-mentioned study, indicate that psychological symptoms in mothers are apparent when their infants are in the NICU, and after their infants' NICU stay. These psychological symptoms and lack of coping skills are even more significant in culturally and linguistically diverse mothers who are parenting a premature infant.

Perinatal and postpartum anxiety and depression for minority women.

From a broader view, this section of the review will address perinatal and postpartum anxiety and depression for all forms of birth, including culturally and linguistically diverse mothers of premature infants. Perinatal depression, depression occurring during or after pregnancy, has a similar occurrence as depression reported during other stages of a women's lives. However, perinatal depression is different from common depression symptoms as it can have an impact on the unborn baby and on the family (Wei, Powell, Freeman, & Holmes, 2011). Common symptoms of depression can include depressed moods, lack of motivation, exhaustion, irritability, weight gain/loss, low energy, hopelessness, and feelings of inadequacy. Perinatal depression can include feeling suicidal, lacking a connection to the unborn infant, or fear of hurting the unborn child for up to a year post-partum (Wei et al., 2011).

In a study conducted by Wei et al., (2011), participants' data were obtained from a county health department in North Carolina between the years of 2002 and 2006. The women in this sample were administered the *Postpartum Depression Screening Scale* (Beck & Gable, 2002), at six weeks postpartum. A total of 586 women were administered the scale to determine group disparities within perinatal depression (Wei et al., 2011). Women living in the county where the data was collected often experience inadequate housing, relationship difficulties, being young mothers, poor pregnancy outcomes, little to no perinatal care, illiteracy, cultural disparity, and poor nutrition (Wei et al., 2011). Out of the 586 women, 52% were Indigenous, 24.2% were Black, 8.7% were white, 13.8% were Hispanic, and 1.2% identified as "other". The Indigenous women were members of the Lumbee Tribe. The results of the analysis indicated that Indigenous women had the highest rates of depression six weeks post-partum (18.7%), with white women (17.6%) and Black women (14.8%) falling slightly lower (Wei et al., 2011). The authors of the study discuss the barriers that Indigenous women encounter and factors that contribute to having higher rates of perinatal depression symptoms. Indigenous women, as well as Black and Hispanic women, are more likely to have inadequate health care, lack of transportation to psychological and related services, inadequate housing, little or no healthcare coverage, poor nutrition, and mistrust for doctors and psychologists (Wei et al., 2011).

Postpartum depression is like perinatal depression, but it occurs within a different timeframe after birth. The authors of a meta-analysis of literature addressing postpartum depression in culturally-linguistically diverse women, indicated that postpartum depression is leading cause of maternal death within the first year after birth in the United States, and that culturally-linguistically diverse women experience higher rates of postpartum depression. Overall, Maxwell, Robinson, and Rogers (2019) conducted a qualitative synthesis of 12 articles. Ultimately, multiple themes emerged, including: the connections between postpartum depression and poverty, connections between culture and postpartum depression, the pressures of motherhood, ability to cope, and keeping their depression to themselves (Maxwell et al., 2019). The themes that emerged from the analysis suggest that although postpartum depression can affect all women, the symptoms of postpartum depression intersecting with the challenges of poverty and disparity can exacerbate the symptoms in underserved women (Maxwell et al., 2019).

Both studies addressing perinatal and postpartum depression highlight the disparities that exist within mental health for mothers who are underserved both culturally and linguistically.

They also acknowledge that Indigenous women in particular face great challenges with depression in motherhood, and that culturally competent practitioners would benefit from continued education regarding mothers’ culture, but also the intersectionality of mental health, motherhood, and poverty.

Summary.

Having a premature infant in the NICU can cause mothers to experience symptoms of anxiety and depression. With pre-existing stressors such as poverty, lack of transportation, or inadequate support that disproportionately impact rural and culturally-linguistically diverse women, trying to overcome perinatal or postpartum depression can be challenging. Underserved and culturally diverse women have more difficulty coping with their infant being in the NICU, they experience higher rates of perinatal and postpartum depression, and they experience consequences because of the intersectionality of poverty and mental health. Indigenous women appear to face great challenges with mental health during motherhood, and many underserved women lack access to necessary services to improve outcomes. As Maxwell et al. (2019) discussed, practitioners must aim to become life-long learners and continue to integrate a mother’s culture into her care and understand intersectionality and the challenges it brings.

Navajo Cultural Traditions and their Influence on Pregnancy and Birth

Navajo women are grounded in their culture and incorporate both Western practices and Navajo beliefs into their daily life. Traditionally, once a Navajo woman knows that she is pregnant, she must first tell her partner. Spiritually, a woman is essentially re-living the Navajo creation story by giving birth to her own child, and therefore must hold pregnancy and birth sacred. Navajo parents are encouraged to avoid “bad” thoughts or engaging in harmful actions, as anything they say or do can impact the unborn infant. The Blessingway Ceremony, performed before or after birth, is done to promote peaceful growth of the unborn child, newborn protection, and survival of the child. Childbirth is a very natural part of Navajo life, and therefore complications or symptoms are not interpreted as negatively as they are in Western culture. Because of this, seeking prenatal care is not always considered or warranted. The Navajo family's main goal is to ensure the safety of the mother and the unborn child (Burns, 2015; Hartle-Schutte 1988; Milligan, 1984)

There are considerations within Navajo culture for pregnant women. They cannot attend certain sings (a healing ritual or chantway), such as the Yei-Be-Chei, or the Night Chant, for those who are ill. Navajo pregnant women try to avoid sick people all together. Navajo mothers try to avoid contact with dead people or animals. Giving birth in or near places where people are sick or could die goes against the Navajo pregnancy beliefs of staying healthy and ensuring the mother and infant's safety. This directly contradicts Western hospitals and practices. (Milligan, 1984).

Navajo women view pregnancy as a natural and normal occurrence in life, and therefore do not allow it to slow them down. Navajo mothers-to-be are often encouraged to remain active and to avoid lying down for long periods of time, as it may cause the baby to grow much bigger than needed and result in a painful delivery. Navajo families do not overly prepare for a baby's arrival, and infants are typically not named until birth, which could be due to historical loss of infants in the past (Milligan, 1984).

Navajo culture promotes the concept of *hozho*, which is the interconnectedness of beauty, harmony, and goodness in all things physical and spiritual. It aids in the health and well-being of all things and beings. When Navajo mothers do not follow cultural considerations, disharmony can result. When a mother has illness, unexplained pain, or nightmares, this may indicate disharmony for the mother and the unborn child. It can imply contact with negative forces, such as sprits. When a child is born prematurely, this can be a sign of disharmony. When this occurs, the infant may be involved in a cleansing ceremony, the Enemy Way, in which they are blackened with ashes. The ceremony is a method of restoring harmony. Other illness or difficulties that occur with infants such as chronic illness or disease, may be considered to result from giving birth in a hospital or may imply that the mother had encountered something harmful to herself or the infant. To address undesirable perinatal complications or outcomes, mothers may seek traditional healing remedies, including curing ceremonies, herbal remedies, or purification rites (Milligan 1984).

Although these cultural practices remain relevant, R. Cruz Begay (2004) described recent changes in knowledge regarding Navajo pregnancy and birth. For example, Begay noted that some older Navajo women had begun to believe that discussing old considerations was “unwholesome” for pregnant women (p. 553). One Navajo woman interviewed by Begay indicated that at one point pregnant women were told to avoid eating tomatoes because tomatoes are the color of blood. However, she laughed at this and indicated that no one worries about this any longer (p. 553) The Blessingway ceremony, mentioned earlier in this section, was often considered to be a prenatal check-up, according to Begay’s (2004) interviewees, and therefore additional prenatal care was not always necessary. Pregnant mothers may choose to go to a typical pre-natal check-up instead of the ceremony to save money, or choose a combination of both (Begay, 2004). During prenatal check-ups, Begay found that Navajo women reported higher levels of comfort when the provider ensured the baby’s well-being. If a provider gave mothers negative information, some mothers would choose another provider to remain in a positive environment (Begay, 2004).

Summary.

While many traditions remain in place, some modern Navajo mothers choose to utilize hospital and Western prenatal services in combination with traditional ceremonies and practice. Culturally competent care on the providers' parts would ensure greater understanding of this balance, or *hozho*, and ensure that mothers feel safe and supported during their pregnancy and birth. If cultural competency is the goal, bridging Western and Traditional medicine in a manner that meets mothers' needs is a solution. In a journal article written by George Hardeen for the *Journal of Indigenous Higher Education* in 1994, Hardeen discusses the everyday happenings at the Chinle Indian Health Service Hospital. Here, traditional practices and Western medicine combine forces to heal and cure Navajo people. During childbirth in the hospital, people in proximity can smell burning cedar, and can often see red and white sashes hanging from the ceilings for mothers to pull on while contracting and giving birth. The sashes transmit good thoughts and help bring women's babies into the world safely (Hardeen, 1994). Medicinemen interviewed in the article discuss that all Navajo people practice traditional medicine, but often use Western medicine to help cure illness when needed. Navajo mothers and families feel they need both (Hardeen, 1994). To bridge traditional and Western medicine, to build trust and to ensure well-being of mothers, it may be crucial for providers to deliver care to Navajo people holistically, in a way that combines traditional values and customs with Western medical approaches. Combining both traditional and Western medicine is, at its best, *hozho* (Hardeen, 1994).

Navajo Mothers and the Societal Challenges

In a study done by Sparks et al. (2009), Black mothers and Indigenous mothers experienced more preterm births than any other racial group in the study, with Indigenous mothers accounting for 22.86% of preterm births compared to white mothers at 9.79%. In terms of poverty, 41.09% of Indigenous mothers are likely to be impacted by poverty when compared to non-Hispanic white (NHW) mothers at 13. 81% (Sparks et al., 2009). While all other racial/ethnic groups received intermediate to adequate prenatal care, Indigenous mothers are the most likely to have no prenatal care and the mostly likely to take advantage of nutrition programs such as Women, Infants, and Children (WIC) (Sparks et al., 2009).

Alexander et al. (2008) found that NA mothers have more maternal risk factors than white mothers and have significantly higher infant mortality rates than both white and Hispanic mothers. The latter statistics could indicate problems in the access to and referral to neonatal follow up care, however sudden infant death syndrome (SIDS) was also mentioned to be a primary cause of infant mortality for Indigenous mothers in the Midwest. Regionally, statistics for Indigenous mothers differ regarding pre-and post-natal care, with Indigenous mothers residing in the Eastern United States, accounting for a slightly higher percentage of preterm births than Indigenous mothers residing in the Western United States.

In Arizona, Indigenous mothers account for 14.2% of preterm births compared to 10.6% for white mothers (March of the Dimes, 2015). Between 2010 and 2013, 12.5% of all preterm births in Arizona occurred in the Northeastern section of the state which includes Navajo Nation’s lands (March of Dimes, 2015). Living on the Navajo reservation often presents logistical challenges for mothers when they have an infant in the NICU. For example, if a mother’s infant is being cared for at Flagstaff Medical Center, and the family lives in Chinle, they are at least a three hour drive one way, depending on their available form of transportation. When the principal investigator for this dissertation study went to visit the Special Care Nursery at Flagstaff Medical Center, providers reported internal observations that Navajo mothers faced specific challenges due to social barriers, including lack of healthcare coverage, living far away from the hospital and therefore being unable to visit frequently, not visiting frequently leading to lack of understanding of infant's care in the NICU, and lack of visiting leading to difficult relationships with NICU staff. The Special Care Nursery staff indicated that finding transportation to and from the hospital for Navajo mothers can be challenging and finding affordable and convenient places to stay while they are here are hard to come by, as the Taylor house (a residentials space for families with infants in the NICU), is limited and often filled (S. Olsen-Zwick, personal communication, October 18, 2018). Unfortunately, little research can be found on the barriers encountered by Navajo mothers as described from their perspectives.

Summary.

Indigenous mothers have higher rates of premature births compared to white mothers, which is also reflected in the state of Arizona and Northern Arizona communities. Ultimately, some of the barriers found in the literature for Indigenous mothers and their premature infants include a lack of prenatal care and their infants being prone to illness and higher infant mortality rates. Ultimately, Navajo mothers face even more unique challenges due to their geographic and rural location in Northern Arizona, which is still mainly undocumented in the literature. This informs one of the main objects of this dissertation study, which is to continue to identify and gain Navajo perspectives and experiences Navajo mothers of premature infants in the Flagstaff Medical Center Special Care Nursery.

CHAPTER 3

METHODOLOGY

Introduction

The purpose of this dissertation study was to explore the lived experiences of Navajo mothers who gave birth to premature infants requiring special care within a Neonatal Intensive Care Unit (NICU). These experiences were gathered from the Navajo mothers themselves, rather than pediatric care providers. The mothers who participated in the study reside on the Navajo Nation particularly within the area of Northeastern Arizona and the Four Corners region. This chapter provides information regarding my ontological and epistemological position on the above-mentioned phenomenon, information regarding my professional background, as well as my subjectivity. Further, described below is information regarding participants, sampling methods, data collection procedures, data analysis, and elements of trustworthiness.

In Chapter 2, I described regionally where the participants reside and background information regarding the Navajo Nation, the impact of historical trauma, the intersection of poverty and rurality in the Southwest, the NICU environment, culturally and linguistically diverse mothers' experiences within the NICU, Navajo family and birthing practices, and social barriers to care and services. These components directly influenced my theoretical orientation of public health psychology, social-ecological resiliency, and Tribal Critical Race Theory. This study aim, grounded in these theoretical orientations, help frame an understanding of how culture, health, and well-being affect Navajo mothers' perinatal experiences in the NICU and when caring for their preterm infants. Therefore, this study's goal was to describe and represent the experiences of Navajo mothers who gave birth to and cared for a premature infant in a rural-serving NICU. The mothers' experiences documented via semi-structured interviews, helped inform the following research questions:

R1: How do Navajo mothers describe their perinatal experiences, including pregnancy and giving birth, while living in rural communities, and when in medical facilities?

R2: How do Navajo mothers describe their postnatal experiences with their premature infant while they are cared for in a rural-serving neonatal intensive care unit?

The dissertation study informed how Navajo mothers experience pregnancy and birth prior to visiting the NICU, how they experience the NICU, and relate to NICU staff. This information may help to inform culturally competent care within the Northern Arizona Healthcare system when treating and developing relationships with Navajo mothers and their premature infants. To address the lived experience of Navajo mothers of preterm infants, I utilized interpretive phenomenological analysis (IPA), to understand and analyze the processes identified through their interviews.

Health inequities, as described for mothers in the review of literature, are often best understood by gathering lived experiences of women (Krieger, 2012). IPA provides an opportunity to understand the lived experiences of the participants themselves, without preformed assumptions or hypotheses. This makes IPA a bottom-up approach, allowing researchers to recognize themes and meanings as they emerge, rather than assigning themes beforehand (Reid, Flowers, & Larkin, 2005). While IPA stems theoretically from phenomenology, it is different in that it relies on the human instinct to engage in self-reflection when participants interpret and process their own experiences (Brocki & Wearden, 2006). IPA is theoretically interpretive due to the researcher's role. When using IPA, the researcher is attempting to understand and step into the participant's world (Reid et al., 2005). However, researchers have their own understanding of the participants and their world, which calls for their own interpretation of the participants' experiences (Reid, et al., 2005). Therefore, it is both phenomenological and interpretive. The approach recognizes that if participants can describe their experiences effectively, and researchers are able to analyze this information, the interpretation may be valid (Brocki & Wearden, 2006). Most qualitative health psychology studies use IPA as a methodological approach, as IPA allows participants to define and place meaning on their health behaviors and experiences. IPA can address "process, rather than adjustment outcome" (Brocki & Wearden, 2006, p. 6). Due to IPA's usefulness within the field of health psychology, I have chosen it specifically for this dissertation study to help me understand and analyze the phenomenon at hand. I have chosen IPA as a methodological approach, as it coincides with my ontological and epistemological assumptions.

Epistemological and Methodological Approach

Researcher's ontological and epistemological assumptions.

A paradigm, or basic beliefs about a phenomenon, encompasses epistemology, ontology, and methodology. Epistemology addresses how others know and see the world. Ontology addresses the relationship between reality and human beings' existence within it, and methodology addresses how the knowledge pertaining to a phenomenon is gained (Denzin & Lincoln, 2013). The above-mentioned concepts should be evaluated and analyzed internally by the researcher to research and question the world around them. Through my professional and clinical experiences, along with my ontological and epistemological beliefs, I am utilizing methodology that aligns with a paradigm, which I deem appropriate for my research questions at hand.

When conducting qualitative research, the researcher's ontological and epistemological assumptions must align with their methodology (Denzin & Lincoln, 2013). My ontological assumptions, or the assumptions I make about the world around me, stem from a constructivist, or interpretivist framework. This framework assumes that there is no truth, or reality, and that any reality that does exist is created by an individual's personal experiences. It assumes that multiple realities exist based the development of these experiences in social and personal contexts (Denzin & Lincoln, 2013). I also believe that the world, and communities within in it, exist in a system that live under the weight of oppression. This oppressive power ultimately forces a gap between the privileged and the oppressed. This gap, and detrimental interactions, can be due to race, ethnicity, socioeconomic status, gender, disability, or sexual identity. This gap is a reality for the oppressed, and lived experiences inform what is known about oppression (Bernal, 2002). Within my work as doctoral student and researcher in maternal and child health, I focus on and look for solutions to health inequities experienced by women and children. Having ontological assumptions in a constructivist framework allows me to address how health inequities are directly related to oppression as a lived experience, particularly for Indigenous women. When Indigenous women's culture and way of life is not valued by the larger system, oppression occurs, and these women experience health inequities. More importantly, oppression against Indigenous women is not a new phenomenon, but a product of intergenerational trauma, that may build upon previous inequities and lived experiences to this day (Peacemaking, 2017).

Epistemology, or the "nature of knowledge", is how the researcher questions where knowledge comes from. How I choose to question where knowledge comes from and perceive information, will influence the choices I make during the research process (Allison & Pomeroy, 2000, p. 92). As a doctoral student in health psychology, I focus on maternal-child health inequities, which directly overlaps with constructivism, which seeks to address individuals' constructed realities. These realities can be centered on health inequities due to ethnicity and gender. This framework interprets lived experiences of oppression from the interaction between the researcher and the participants. My epistemological assumption is that Indigenous women are shaped by their lived experiences of oppression, and these experiences can be understood through what I know as a researcher, and what the participants share with me about their own health inequities (Denzin & Lincoln, 2013). As a doctoral student addressing health inequities, I believe that I must understand the social structures that Indigenous women experience and the oppression that occurs within these structures, before I can address change. I believe that, ultimately, the knowledge I gain from studying Indigenous women's experiences with inequities and oppression, can inform practice and policy that impact them, and ultimately the social structures they exist in. I believe that reproductive justice and advocacy is possible, if researchers and practitioners listen to and give agency to Indigenous women's lived experiences (Denzin & Lincoln, 2013). From both my ontological and epistemological beliefs, I find myself operating from a constructivist paradigm for this dissertation study.

Researcher Positionality

Research often focuses on participant subjectivity and how it affects the data, however, quality and rigor in a study depend on researcher subjectivity (Muhammad et al., 2015). To address researcher subjectivity, the investigator uses reflexivity to determine what their motive is for the study at hand, what is the researcher's experiences, or their motivation when addressing the phenomenon of the study (Gough & Madill, 2012). Gough and Madill (2012, p. 18) discuss how reflexivity functions from the belief that individuals have "access" to their own experiences and biases. When researchers can be transparent with themselves, their participants, and their audience, it can positively improve overall research findings. This form of higher-level cognition, or critical thinking for researchers, allows the intersection of professional and theoretical identity to come to the forefront, while checking for bias and personal judgement within the overall research process (Gough & Madill 2012). Identifying and analyzing the researcher's "relationship with the phenomenon" at hand is the goal of reflexivity. Researcher reflexivity is synonymous with research quality (Gough & Madill, 2012, p. 21). To engage in reflexivity, I will describe my professional background and subjectivity below.

Professional background.

I am a doctoral student in a combined Counseling Psychology and School Psychology Ph.D. program at Northern Arizona University. I hold a Bachelor of Science degree in Speech and Hearing Science from Arizona State University. I am currently a pre-doctoral intern at the University of New Mexico Center for Development and Disability (CDD), and plan to continue my training at the CDD as a postdoctoral fellow in early childhood mental health. My early career as a Speech-Language Pathology Assistant is where I began working with children in both rehabilitative, school, and juvenile detention settings. My work as a doctoral student has allowed me to work with children and families from rural communities in Northern Arizona, including the Navajo and Hopi nations, in the context of developmental evaluations, mental health counseling, and maternal-child health outreach. As a previous fellow in the University of Arizona's Leadership and Education in Neurodevelopmental and Related Disorders program (ArizonaLEND), I developed interest and skills in maternal-child public health and health inequities. These skills include incorporating multicultural understanding with health behaviors to conduct evidenced-based approaches. Public health involves delving into the root of health inequities such as premature births or genetic conditions, finding solutions for rural populations including partnering with community stakeholders and conducting direct outreach, and engaging in public health policy at a local, state, and national levels (Cashman et al., 2008).

Subjectivity.

Due to my professional background and experiences, I have a strong interest in impacting and altering maternal-child health policy and informing culturally competent healthcare and psychological practices. I think a quality approach to creating change in policy and practice is to gather data and information directly from those experiencing health inequities. I believe by conducting exploratory studies, researchers can identify themes and connections through mothers' experiences that can later inform evidenced-based health interventions. I believe that for health practitioners to deliver culturally competent care, they must first be *competent* in their patients' culture (Chino & DeBruyn, 2006). I believe both mothers and practitioners are at a disadvantage when community health care is not culturally competent, and that lack of informed care is not a sustainable way to function in rural communities. Given that Indigenous mothers and Black mothers are currently having the highest percentage of premature births in the United States (Sparks et al., 2009), and the overall lack of research addressing these mothers' needs and values in pediatric care settings, I think it is necessary for practitioners and scholars in maternal and child health to address this gap to impact premature birth inequities in the long run. Furthermore, I believe that the lack of culturally competent care in pediatric care settings informs an overall power dynamic between practitioners and culturally and linguistically diverse mothers. Ultimately, I believe that equipping Northern Arizona healthcare practitioners with cultural knowledge of Indigenous practices, values, and beliefs during the perinatal period, can create a foundation for positive mother-practitioner relationships in pediatric care settings.

The professional experiences I have had to date have influenced my interest and passion for the phenomenon being addressed by this dissertation. As an undergraduate student, I began my work in the disability field, engaging with both children and individuals with disabilities and their families. I began to invest time and energy into learning about and advocating for disability culture and community. Once in graduate school, I explored the intersection of gender, culture, and disability, and how it informed my own practice as a future health psychologist, particularly with rural, Indigenous populations. As I developed an interest and skillset in early intervention services for children with disabilities, I noticed the power and importance of the parents, especially mothers, in a child's overall well-being and growth. From there, I explored early intervention from an even earlier perspective: pregnancy and birth, and the experiences mothers have, and the knowledge they receive, when giving birth to a child who is at-risk for developmental disabilities.

I cannot discuss my subjectivity as a researcher without disclosing that I have a strong passion for neonatal care and developmental follow-up. As a fellow in the ArizonaLEND program, I was introduced to the role a psychologist can play in an infant's life and the family-centered practices that can be implemented in pediatric settings. The beginning of a premature infant's life is truly a series of connections and relationships that practitioners and service providers create with mothers and families. These relationships rely on trust, commitment, and an understanding of the family's cultural practices and beliefs. I believe that if Indigenous mothers can start their infant's care with a supportive, nurturing, and culturally centered relationship with their infant's providers, this can positively impact health inequities in the long run and increase the chances for families to access follow-up developmental services for their children. As a clinician who has been trained in Western medical and psychological care, I acknowledge that I have a bias toward this type of training, particularly if it does not include culturally responsive and evidenced based approaches. Some of these approaches include Infant Mental Health with mothers of premature infants or high-risk pregnancies, or the use of Cognitive Behavioral Therapy in individual treatment settings. However, I also have to acknowledge that as a white practitioner, I can accept and embrace Indigenous approaches to treatment, but that I cannot implement them myself. Therefore, I must be reflective and open to listening and hearing Indigenous families' perspectives and considerations.

When outlining my positionality, it is important to summarize my initial assumptions and biases when going into this study. Before analyzing the data, I assumed that the participants would discuss rurality in-depth, including how the interacted with rural communities and how living in rural communities could impact their access to quality healthcare. Furthermore, I assumed the mothers would have negative feelings and memories associated with their experiences with NICU staff, as research in the literature review outlined. Additionally, I assumed that the mothers would talk more about the NICU experience than the pregnancy and the birth.

Participants

Study participants.

The participants for this dissertation study were three Navajo mothers, aged 25, 28, and 29. Purposeful sampling was used due to the limited number of mothers in the Northern Arizona Healthcare Flagstaff Medical Center's (NAH FMC) Special Care Nursery, and to ensure all mothers meet the inclusion criteria described next. The Special Care Nursery is described further within the procedures section. To be included in this research study, the mothers had to give birth to a premature infant, meaning the infant was born before 37 weeks gestation. Mothers eligible for participation had infants who graduated from the NICU up to a year later from the onset of the study. Developers of IPA suggest a sample size of no more than 10 participants for researchers to retain an overall picture of each individual and position themes within their narrative. With those conducting their dissertations, a range of participants between three and five is appropriate (Brocki & Wearden, 2006; Smith et al., 1999), and therefore after several recruitment limitations, three mothers participated in this dissertation.

Purposeful sampling techniques assisted in obtaining participants for this study. Although purposeful sampling is often used in qualitative psychological research, a limitation with this form of sampling is that it reduces generalizability, or inappropriate generalizations can be made by qualitative researchers (Robinson, 2014). Recruitment of participants involved both the researcher, Flagstaff Medical Center Special Care Nursery staff, and other individuals in the community who work with Navajo mothers of preterm infants. Recruitment occurred directly through the principal investigator, the FMC NICU staff and community practitioners. Recruitment involved a multi-step process. First, the principal investigator sent an email with a recruitment flyer to the FMC NICU developmental specialist. The developmental specialist handed out flyers to all Navajo mothers who she believed were eligible for participation. The principal investigator also prepared recruitment flyers in pre-stamped envelopes that the developmental specialist and community practitioners could mail directly to mothers who were potential participants. The Navajo mothers utilized the principal investigator’s contact information on the email or paper flyer and reached out to the principal investigator to request more information around participating in the study. The principal investigator included her name, email address, physical address, and phone number to be reached by potential mothers. A standardized script was used with each mother to describe the study and what participation entailed. Furthermore, recruitment efforts were done using targeted ads on Facebook and the Navajo Times. Specific recruitment criteria were listed and mothers reached out to the principal investigator if they sought more information and/or wanted to participate in the study. The recruitment flyer and the newspaper ads are included in the appendices.

After a meeting with several staff members including the developmental specialist, a neonatal nurse, and the director of FMC IRB, it was decided the researcher would obtain consent directly in the NICU. However, due to recent recruitment strains, including having historically low numbers in the FMC NICU and having COVID-19 cases at FMC, informed consent was obtained via email by emailing the mothers a signed PDF consent. If the mothers are unable to use computers for participation, the informed consent could be mailed, and then participation would only occur until the principal investigator had received the consent back. Attached to the informed consent, the mothers found a demographics sheet that included pertinent information regarding age, marital status, education, and information regarding the distance they live from a hospital and other questions. Once the consent was signed, the mother filled this out and sent the consent and this information back to the principal investigator. Like discussed previously, this information could be sent back via email or mail. This demographics sheet is in the appendices. Once consent was obtained, all mothers were given an identification number and pseudonym to ensure confidentiality and all further correspondence was done using this identification number.

For this study, homogeneity of the study population (i.e., Navajo mothers), was achieved by having strict inclusion and exclusion criteria, to make accurate generalization from the sample to the target population. To be included in this research study, the mothers must have given birth to a premature infant, meaning the infant was born before 37 weeks gestation, with their infants hospitalized up to one year prior to the start of the study, in the NAH FMC Special Care Nursery.

The purpose of this study was to explore Navajo mother's experiences, and therefore, the generalizations from this study's participants will inform implications for Navajo mothers living in the rural Southwest.

Financial honoraria.

Participating mothers received gift cards to Walmart stores. On the informed consents, the mother had information regarding a gift card. All mothers participating in the study received a gift card for $100. The gift card was mailed to the mother after the interview. A log of the gift card number, when it was mailed, and the participant's signature, was used to keep track of financial honoraria.

Researcher-participant relationship.

To establish the researcher-participant relationship, I introduced myself as a doctoral student in Counseling/School Psychology in the College of Education at Northern Arizona University. I disclosed that I am not a licensed psychologist, but a doctoral student conducting my dissertation study. I informed them that I am interested in exploring Navajo mothers' experiences when giving birth to a premature infant to inform culturally competent care within the Northern Arizona Healthcare system. I built trust and rapport with participants through active listening, empathy, and engaged discussions around motherhood, premature infants, and their experiences in the NAH FMC Special Care Nursery. As a researcher and student, I explored and learned from the literature regarding oppression of Indigenous women, the history, and important events for the Diné people, and engaged in cultural humility (i.e., recognizing others' cultural identity), to build sustainable relationships with the participants. I learned and used opening and closing greetings in Diné to create a sense of safety and trust, and to impart my gratitude for their time and stories. I utilized a script when reviewing the informed consent and before conducting interviews with participants.

Sample characteristics.

Table 1
Sample characteristics

Question from demographic sheet	Navajo Mothers *n* = 3
Average Age (years)	27.3
Education	
No schooling completed	1
Nursery school to 8th grade	0
Some high school, no diploma	0
High school graduate, diploma, or the equivalent	0
Some college credit, no degree	2
Associate degree	0
Bachelor's degree	0
Master's degree	0
Professional degree	0
Doctoral degree	0
Marital Status	
Single, never married	2
Married or domestic partnership	0
Common law	1
Widowed	0
Divorced	0
Separated	0
Employment	
Employed for wages	1
Self-employed	1
Out of work	0
Looking for work	0
A homemaker	1
Student	0
Miltary	0
Retired	0
Unable to work	0
Household Income	
Greater than $60,000	0
$40,000-$60,000	0
$20,000-$40,000	1
Less than $20,000	2
Distance from a major city	
Less than 50 miles	0
50-100 miles	3
100-150 miles	0
200-250 miles	0
More than 200 miles	0
Other children at home	
Yes	3
No	0

Note. This table reports the demographics of Navajo mothers that participated in the study. There were three mothers total and all values (except age) represent the number of participants falling into each category.

Data Collection Procedures

Institutional review boards and human subjects' protections.

This dissertation study went through the approval processes of the Navajo Nation Human Research Review Board (NNHRRB), the Northern Arizona University Institutional Review Board (NAU IRB), and the FMC IRB. I, along with members of my dissertation committee, was successful in the process of obtaining permission from the above-mentioned institutional review boards. For the NNHRRB, approval from two Navajo Nation Agency Councils is required for submission to the review board. I obtained the approval from the Western Navajo Agency Council and the Chinle (Central) Agency Council. Myself, along with members of my dissertation committee, attended both of above-mentioned council's agency meetings to discuss the study with various Navajo Chapters and council members to obtain approval. My dissertation chair and I obtained approval to submit the study to the FMC IRB by allowing Special Care Nursery staff and the IRB chair to read the study proposal and request any changes or additions to the proposal to best support the organization. NAU IRB requires researchers to consult with Dr. Chad Hammill regarding submission of the study to NNHRRB before submitting the study to NAU IRB. All IRB submissions were simultaneous. Approval from NAH IRB and FMC IRB were obtained in the Fall of 2019, and approval from the NNHRRB was obtained in January of 2020. It is important to note that NNHRRB requires the principal investigator to disseminate the research back to the Navajo Nation and subsequent reservation stakeholders within maternal and child health departments and organizations. Discussion of this was noted in both agency council meetings attended by the principal investigator, along with valid frustrations from tribal members regarding this issue. Therefore, all results obtained from this study plan to be disseminated to the Navajo Nation to sustainably support their mothers and infants. Informed consent with approval from all three review boards were provided to the mothers prior to data collection.

Informed consent.

Informed consent was obtained prior to data collection. Informed consent included permission to digitally record the mothers' interviews. The mothers were given identification numbers and pseudonyms to ensure anonymity and protection of information. Digital recordings were immediately following transcription and analysis. Pertinent demographics for the study participants, including age, level of education, use of public assistance, and former births, were included as an extra document in the informed consent. Please see the demographics sheet in Appendix A. The informed consent was given and signed via email by all three participants.

Interviews

In-depth, semi-structured interviews were conducted with the mothers. Due to recent recruitment strains, including having historically low numbers in the NICU and due to COVID-19 cases at FMC, the interviews were conducted using VSee (a HIPAA compliant telemedicine video solution like Zoom). These interviews were digitally recorded to aid in transcription and analysis after data collection. The semi-structured interviews were created along with a cultural consultant, Aurilia Calamity, a developmental specialist with the Navajo nation early intervention program, to ensure the primary investigator was maintaining culturally appropriate context and respect for what was asked of the mother. The mothers were only approached for interviews after it had been determined that their infant is medically stable. The semi-structured interviews contained broad and open-ended questions to help ensure the mother had a say in how much she chose to answer and how she chose to answer. Interview probes were used to gather more information. Semi-structured interviews, and a combination of structured and unstructured questions, ensured my ability to answer the two research questions. The semi-structured interview questions were created using the research questions as a foundation. Each question directly aimed to answer the different parts of the research questions, whether that was discussing prenatal experiences, NICU experiences, and any other information around visiting and caring for the infant and the mothers' perspectives.

The semi-structured interview for this dissertation study allowed the mothers to provide their perspectives and experiences on the perinatal period in a rural setting, and their postnatal experiences while their infant was in the NICU. Ultimately, the primary focus of the semi-structured interview was to provide a space for the mothers to share their experiences in the perinatal period, including pregnancy and birth, and postnatal experiences in the NICU, and ultimately to identify factors associated with Navajo mothers' ability to navigate the NICU environment.

Analytic memos.

Writing analytic memos is an important aspect to qualitative research. It allows the researcher to document and reflect upon the organization, analysis, and synthesis of the data. This can include the coding process, choices made, and any themes that emerge and are identified (Saldaña, 2016). The process of analytic memo writing ensures transparency and allows replication of the study. It is a way to ensure that researcher bias is not being prematurely integrated into the overall analysis, and a way for the researcher to check their assumptions (Saldaña, 2016). I engaged in analytic memo writing after each interview to accurately document my process of coding and identifying themes from the data. When engaging in analytic memo writing, I found myself being reflective in my thoughts and initial formations of themes. This process allowed me to use my past notes and observations to inform new ideas that emerged from the transcriptions. Documenting my own emotional reactions and thoughts during interviews caused me to realize I was making assumptions based on my experiences and knowledge. For example, I assumed the participants would describe more experiences impacted by rurality, however, I later found out and was surprised by the fact that the participants' prenatal experiences were salient for them.

Data Analysis

Interpretative phenomenological analysis.

Interpretive Phenomenological Analysis (IPA), unlike other qualitative approaches, gives the researcher an opportunity to not only explore lived experiences of participants, but to engage in a process of interpretation of results that is both reflective and subjective (Reid et al., 2005). This means the researcher "enters into the research process" (Reid et al., 2005, p. 20). Interpretations conducted with IPA are done in a cultural context, while not only allowing for meanings to emerge, but for evidence regarding the participants' behaviors and feelings to emerge as well (Reid et al., 2005). Interpretations using IPA for this dissertation study were grounded within constructivist paradigm while still existing within the participants' experiences.

The goal of IPA is to hear of the lived experiences of participants within a cultural context. Participants must understand their role in the research process, why the study is being conducted, give consent, and have a motivation to share their experiences with others (Reid et al., 2005; Smith et al., 1999). Reid and colleagues (2005), along with Smith and colleagues (1999) describe the search for meaning in IPA "…surpasses any objective truth or reality" (p. 22). When analyzing qualitative data using IPA, it is important to pull key excerpts from the participant's interviews. The number of excerpts pulled depends solely on the number of participants and the amount of information shared. IPA is both inductive and iterative which provides an opportunity for the researcher to have an “insider perspective” (Reid et al., 2005, p. 22; Smith el al., 1999). The researcher must take an insider’s perspective, and subsequently insert their analysis and interpretation as to why their participants are having these lived experiences within the context of the phenomenon being studied.

Reid et al. (2005) indicated there is both an emic stance and etic stance within IPA. The emic stance, or the insider stance, “prioritizes the participants’ world view at the core of the account” (p. 22), while the etic, or interpretive stance, allows the researcher to give light as to why these experiences are occurring and to focus in on a specific research question. IPA involves several steps, including organizing the data, coding the data, and interpretation of the data by the researcher. As discussed in earlier sections of the methodology chapter, transparency and reflexivity in the researcher’s interpretation is a necessary methodological approach when using IPA. It is an indicator for quality research. Cross-validation can be done through an independent audit of the researcher’s analysis to establish validity in the results obtained (Reid et al., 2005; Smith et al., 1999). After an analysis has been conducted, the themes that emerged from the research process are organized into a table or visual model. These themes should attempt to address the consistency across participants’ experiences, but also explain variation within them (Reid et al., 2005; Smith et al., 1999).

Organizing, analyzing, and synthesizing data.

The process of IPA involves transcribing interviews and identifying themes, finding connections, visually displaying themes, and writing up the results. The following section will discuss each of these steps in depth, however, the steps the researcher went through for each interview when conducting IPA are also listed below:

Step one: First, the researcher printed out the transcript, and while listening to the recording, read and re-read the transcripts multiple times. During this step, the researcher makes notes in the margins regarding linguistic factors such as pauses in speech and capturing tone. Emotion is also documented here.

Step two: Here, the researcher did not listen to the audio recording, and went back to read the transcript again while simultaneously noting in the margins any comments or questions that occur for them, highlighting important quotes, and while starting to list initial emerging themes.

Step three: Now, the researcher started clustering interesting quotes together under emergent themes while utilizing notes they made in the margins to help them inform and support the emergent themes that they find.

Step four: Once done with the first participant's transcription, the researcher engaged in reflexivity and used bracketing, a way to pretend you forgot about the last participant you analyzed, and you approach your new participant's transcript with a fresh approach. By doing this, the researcher honored each participant and their individual voice.

Step five: Once the researcher individually analyzed all of the transcripts, they searched for themes and similarities across participants, along with divergence and convergence of themes.

Identifying initial themes.

After transcribing the semi-structured interviews, the researcher read the transcriptions through multiple times, while making detailed notes in the margins, noting what emerged and what stood out, while simultaneously listening to the recorded interviews. Smith, Jarmin, and Osborne (1999) indicate that reading the transcription multiple times allows for a level of intimacy to emerge with the respondents and the data at hand. The researcher documented emerging theme titles using key words and phrases in the transcription. During this step of the analysis, everything within the transcriptions was deemed as useful and important to the overall interpretation (Smith et al., 1999).

Identifying connections.

After the transcription was combed multiple times for emerging themes, these themes were listed separately from the transcription by the researcher. The researcher then searched for connections between the themes identified. The researcher combined the themes that aligned and went together, and identified some themes as single concepts (Smith et al., 1999). The researcher made sure to link the connections they found to the transcript and what the participants actually said to ensure accurate interpretation.

Creating a table of themes.

After initial themes and connections were identified, a table of themes was created to organize and display the themes accurately. The researcher placed in the table superordinate themes and sub-themes that emerged beneath them. The researcher ensured accuracy and reduced bias by always going back to the transcript and ensured the identified themes corresponded to respondents’ data. While engaging in this process, the researcher removed themes, as necessary. The researcher documented the number of important transcript quotes that occurred for each theme (Smith et al.,1999). Smith and colleagues (1999) indicate that this form of analysis is organic and ever changing, and the interviews can be changed and altered as themes emerge and are removed, and the researcher engaged in this aspect of the analysis often. This interpretive process resulted in the creation of a master list of themes at the end of data collection (Smith, et al., 1999).

Writing up master list of themes.

This portion of data analysis involved turning the identified themes into an overall narrative. It is a way to organize the data that can inform an audience, and to conceptualize the phenomenon at hand and its importance to the field of health psychology. The researcher identified what was truly essential from the overall analysis and shared the respondents' experiences (Smith et al., 1999). The researcher wrote up the connections made between verbatim pieces from the transcription and the themes interpreted from them. The researcher discussed the major themes, their sub-themes, and provided data to back up the interpretation (Smith et al., 1999).

Data Organization and Protection

The data was organized by using Microsoft Word, Excel and NVivo qualitative data analysis software. Microsoft Word was used to organize and document interviews and transcriptions while Microsoft Excel will be used to organize and document the emergence of themes and the master list of themes.

To ensure confidentiality, I gave participants identification numbers and also pseudonyms to use in the findings section. These numbers were provided immediately after consent was obtained. I password protected all interviews and documents associated with the study and stored this information on a password-protected external hard drive. Since the interviews were conducted via the VSee or emailed document, I ensured file names and in-person names were confidential and remained anonymous using identification numbers. If the mother requested to sign an informed consent through a written letter, a de-identified and pre-stamped envelope was sent to the mother which she then utilized to send her information back. The envelope, the informed consent and subsequent demographics sheet only contained her identification number and her address. If the mother requested to sign the informed consent via email and use of a signable PDF, the mother's email was deleted, and the document was then saved on the hard drive as the mother's identification number and all personal information was removed.

Trustworthiness of Study

Confidence in one's research findings can be done by establishing trustworthiness. According to Lincoln and Guba (1985), trustworthiness has the following components: credibility, transferability, dependability, neutrality, and confirmability. Guba (1981) raised four questions regarding trustworthiness that every researcher needs to ask regardless of methodology chosen. These include: 1) how can a researcher create confidence in the findings, 2) how does a researcher determine how applicable the findings would be within other settings or contexts, 3) how can a researcher know if the findings could be replicated with the same participants in the same context, and 4) how can a researcher know if the findings coming from the investigation was not influenced by bias or the researcher's motivation. Below, is a justification for how to answer these questions and tools used to enhance trustworthiness.

Credibility.

Establishing credibility is essential to creating trustworthiness within the research study and can be done through several ways (Lincoln & Guba, 1985). Anney (2015) defined credibility as "the confidence that can be placed in the truth of the research findings" (p. 276).

One way is to choose an appropriate methodology for the study at hand. For this dissertation study, a qualitative approach was deemed the most appropriate due to its exploratory nature. Qualitative data collection and analysis allows for the mother's experiences to understood and documented.

During the analysis, I documented my process of finding meaning units from the data. Constructing meaning units that are not too broad, nor too small, ensures credibility of the findings.

Another way to ensure credibility is through member-checks. Member checks ensure that data and interpretations were consistently examined as they were collected from members of the participant groups pertaining to the study. This is a technique in which the data, interpretations, and conclusions are shared with the participants. It allows participants to clarify what their intentions were, correct errors, and provide additional information if necessary; the participants can judge the credibility of your results. Unfortunately, colonization is ever present in exploratory studies of marginalized groups. Subsequently, member checks can be used to give participants voice and choice during the data collection process. Participants can ensure they are being represented in a way that is culturally appropriate and valuable for their communities. After the data was collected, I sent the results back to the mothers to determine if they agreed with the analysis or felt changes were needed. At this time, none of the participants have been able to respond to my request, so I can safely assume the interpretation is acceptable for them.

Due to the novelty of my involvement in neonatal and maternal health research, I cannot utilize prolonged engagement. However, I can use other forms of credibility including peer debriefing. This process gives me the opportunity as the researcher to obtain the perceptions and insight of my dissertation committee, department faculty, and colleagues, when developing my results and conclusions of this study. For this study, Dr. Darold Joseph provided in-depth consultation and reflection, along with pertinent resources to help guide and address my analysis.

Reflexivity was used before and after interviews were conducted to address my own biases and worldview and to separate my interpretations of the phenomenon from the participants' (Denzin & Lincoln, 2013). Finally, the process of persistent observation was used to ensure extended interaction with the environment, phenomenon, and participants, to help me gain a better understanding of the setting at hand (Anney, 2015).

Transferability.

Transferability is synonymous with generalizability or external validity in quantitative research. It is how the researcher provides evidence that the study could be applicable in different contexts, situations, times, or populations. The researcher can only support the applicability of their study and results by providing necessary data, and they can do this by ensuring the methods (i.e., description of participants, regional areas, and data collection processes) are explained in sufficient detail (Lincoln & Guba, 1985). This entails accurately embedding the data in a descriptive and detailed context of the population itself and the setting in which the study is conducted. I did this by describing the Navajo Nation, the communities in which the mothers reside, the NICU setting, the hospital setting, and the demographic information of the Navajo mothers participating. By providing detailed methodological descriptions, I enable future researchers to conduct similar studies of their own and to evaluate if the finds are valid and transferable in different areas of study (Kline, 2008). Therefore, this study also includes detailed descriptions of participants, contexts, and the phenomenon at hand. Furthermore, purposeful sampling was used to ensure the data is coming from case-specific individuals who can shed the best light upon the phenomenon being studied. This method of sampling provides more in-depth findings than other sampling methods (Anney, 2015).

Dependability.

Dependability is the idea that the same study could be conducted again and have similar results (Golafshani, 2003). It ensures the consistency of interpretations over time. To ensure dependability, I provided a detailed methodological process by which the study is to be conducted. This allows future researchers to replicate the dissertation study. The principles and criteria used to select participants were detailed in the methodology, along with the participant's main characteristics, for future use.

Golafshani (2003) indicates by using process notes, journaling the interpretive process, and organizing raw data can allow for others to audit your research process and ensure dependability. In addition, a pilot interview was conducted with the first participant to ensure the interview is reliable and useful as a qualitative tool. Audit trials were used to validate the data collected, in particular, using an external auditor. To ensure a successful audit, my raw data, interview notes, observation notes, and other documents from the field, were kept and reviewed. This was done to hold myself as the researcher accountable, and to confirm research decisions and activities (Anney, 2015). The external auditor can be another faculty unfamiliar with my dissertation topic within the College of Education. For myself, Dr. Darold Joseph filled the role as my external auditor, and engaged with me during the analysis process to ensure accountability and meaningful interpretation.

Confirmability.

Confirmability is how well an outside audience can support the results of a study. It refers to the level to which results obtained can be corroborated by other researchers and experts in the field (Anney, 2015; Krefting, 1991). This aspect of trustworthiness ensures that the interpretations are derived only from the data. Neutrality is a useful strategy in establishing confirmability, as it requires a neutral stance, and outside perspective to fully establish validity (Krefting, 1991). Ways to engage in neutrality include using audit trials and reflexive journaling. Allowing one external auditor or colleague to weigh in on the chosen meaning units and themes from the analysis will also ensure confirmability in overall findings (Lincoln & Guba, 1985). The external auditor can be another faculty unfamiliar with my dissertation topic within the College of Education. For myself, Dr. Darold Joseph filled the role as my external auditor, and engaged with me during the analysis process to ensure accountability and meaningful interpretation.

Dr. Joseph provided critical and thoughtful feedback that impacted my growth and insight during the analysis process. More specifically, Dr. Joseph supported the findings and final themes, but provided me with further feedback and resources to develop a deeper understanding of the participants' narratives and their role in understanding the phenomenon at hand. Dr. Joseph provided important feedback regarding my research questions that specifically focused on the context of Navajo mothers' lives (i.e., rurality, hospital stays, the NICU, perinatal versus prenatal time periods), and how those contexts intersected with their narratives. Additionally, Dr. Joseph asked me important questions directed at my emerging themes, particularly around how Indigenous culture and beliefs shaped the Navajo mothers' narratives, and how that can be equitably described in the results and discussion. These questions directly related to my understanding and knowledge around the intersection of historical trauma, the relationship between U.S. and white systems of oppression and Indigenous peoples, and ultimately Indigenous resilience. This process and time with Dr. Joseph was extremely important to my own growth and reflection throughout this study, but also in my ability to be an equitable researcher and ally.

Furthermore, Dr. Joseph provided me with irreplaceable resources and research regarding Indigenous resilience and the sustainable impact of resilience on equitable healthcare for Indigenous people. Salient resources shared with me by Dr. Joseph was included but not limited to information regarding Tribal Critical Race Theory (Brayboy, 2006) and a review of research addressing individual and collective Indigenous resilience (Teufel-Shone et al., 2016).

Reflexive thinking and journaling will be discussed below to further understand the concept of neutrality within the dissertation study.

Neutrality.

Neutrality refers to the idea that the research or results are not burdened by biases. Neutrality ensures the research is coming only from the participants' perspective, and has no other outside motivation (Krefting, 1991). To ensure this, researchers need to engage in reflexivity, or the process of internally analyzing their own experiences and perspectives. (Krefting, 1991). As outlined in previous sections of the methodology chapter, I discussed my assumptions and beliefs regarding health inequities, and attempted to keep my beliefs and assumptions separate from what I gathered from the participants. Furthermore, I engaged in reflexive journaling to write and keep reflexive documents "…in order to reflect on, tentatively interpret, and plan data collection" (Wallendorf & Belk, 1989, p. 77). This journal included personal reflections on the process and the study, and personal influences that potentially arose due to researcher bias (Anney, 2015).

Chapter Summary

There is currently a gap in the research regarding culturally and linguistically diverse mothers' experiences when giving birth to premature infants in rural settings. There is little to no research regarding Navajo mothers' experiences. By utilizing an interpretive phenomenological approach, Navajo mothers' lived experiences were explored and used to inform culturally competent care, public health policy, and community outreach.

CHAPTER 4

FINDINGS AND RESULTS

Summary of Findings

Three Navajo mothers of preterm infants sat down and told their story during an hour-long interview with the principal investigator. Aged 25, 28, and 29, and all residing on the Navajo Nation, the mothers gave insight into what it is like to be pregnant, give birth, and navigate a NICU, all through their individual perspectives. Their stories became transcripts, and the transcripts became the meaning behind the findings discussed below.

Three super-ordinate themes emerged from the exploration of Navajo mothers' experiences when giving birth to and caring for their preterm infants in a rural-serving neonatal intensive care unit. The first theme, (1) perinatal challenges prior to the NICU stay, had two sub themes: (a) complicated pregnancy and (b) complicated birth. The second theme, (2) the NICU experience, had three sub-themes: (a) perceptions of medical interventions, (b) helpful clinical staff, and (c) reduction of barriers to care. The final and third superordinate theme, (3) perinatal resiliency, had five sub-themes: (a) cultural resiliency, (b) emotional vulnerability, (c) maternal empowerment, (d) support from the family system, and (e) COVID-19. See table two for a master list of themes and the numbers and percentages of quotes related to the theme provided by each mother. These themes accurately capture the three mother's lived experiences while being pregnant with and giving birth to their preterm infant, and their experiences while interacting with NICU staff and caring for their preterm infant in a rural-serving NICU.

To help navigate the reader through the findings, this section will be structured by highlighting highlight the cases within the themes as one narrative. Furthermore, the themes, and how the mothers experienced them, will be presented in the order of a typical preterm perinatal timeline: pregnancy, birth, the NICU stay, and reflection on the experiences. The mothers were given pseudonyms to help protect their identity, while also helping readers give a name to the story that was told.

Perinatal challenges prior to the NICU stay

This theme defines the period of time during the mothers' lives that is the perinatal period, more specifically related to pregnancy and birth. This theme relates to experiences the mothers had that were more challenging and or emotionally taxing. When exploring perinatal challenges prior to the NICU stay, each mother shared a story of a challenging pregnancy and birth. Associated with the sub-theme *challenging pregnancy*, Diana described how and when she found out her baby was to be born premature, which is considered to be a high-risk pregnancy:

> "…there the midwife told me that because I was only 34, 34 ½ weeks, they were gonna get me transported to a different hospital, because my baby, she was going to be premature."

Here, Diana discussed the impact of having a premature infant and the impact it has on her pregnancy story. In particular, Diana was speaking to rurality when she discussed being "transported" to another hospital. Cori also found her pregnancy experience intersected with rurality, and identified ways in which rurality made the experience unpredictable and out of her control, "So me being 34 weeks pregnant I couldn't deliver there in Tuba City, so I was air lifted to Flagstaff Medical Center in a helicopter." In Northern Arizona, there are limited NICUs able to treat certain high-risk mothers and infants, and those mothers often must be transported from the Navajo Nation to Flagstaff Medical Center and the Special Care Nursery, or further. Diana went on to describe how some aspects of her pregnancy were unexpected and painful, as she shared that she had “pain around my pelvis that made it really uncomfortable.” She described an accident where she had to follow up with the doctor in which “it had rained, and I went outside, and I ended up slipping in the mud.”

Similarly, Cori shared what it was like to have personal health concerns that impacted her baby’s gestation and finding out her infant was premature:

> “By the time my 3rd trimester began I was diagnosed with Preeclampsia which meant I had high blood pressure but wasn’t prescribed any medication for which meant I would most likely deliver early.”

Having a preterm infant oftentimes indicates your pregnancy is or will be high risk. When living in more rural areas like the Navajo Nation, not all hospitals are equipped to handle more high-risk births, and therefore, mothers need to be transported to other locations to keep them safe and healthy. Interestingly, Cori also shared her surprise at the fact that she was pregnant at all. Indicating that at one point she did not think she could be a mother. Cori remembers, “When I found out I was pregnant it came as a surprise because about [] years ago I had a really bad accident where I fell off the horse and he ran over me and I got really hurt.”

Renee also reflected on what was a *challenging pregnancy* for herself, and she shared the news she received from the doctor after she had not been showing around six months of pregnancy:

> “…so from there they had to send us back to the hospital and come to find out, I guess there was something going on with the umbilical cord, it wasn’t functioning well enough to give the baby the nutrients he wanted.”

Earlier in her story, Renee shared that after talking with family, maybe the baby was a girl and that is why they were so small. However, in the above reflection, it appeared there was something much more concerning. Now that the pregnancy was high risk, Renee remembered, “and they’re [doctors] like, I think you just, you know, need to check back into the hospital and then from there they’re like, we’re going to have to give you the steroid shot just because the baby’s so small, the baby will have to come out a little early.” Renee identified the experience of discovering her infant was premature as overwhelming and she shared her interaction with her husband, “he [her husband] calmed me down and I was like, okay, and the doctors wanted us to stay there until I was at least 37 or 38 weeks, for the baby’s lungs to be like mature enough to be strong.”

Unlike the other two mothers, Renee’s pregnancy continued to become more complicated. Renee remembers having to do fetal diagnostic testing, and shared, “so when they had to get some of that amniotic fluid with the needle, it was really hard to get because I was very low on it… and they had to really kind of push down my stomach and try to get some fluid, like in a place where they can actually get some, so it was painful.” Renee identified finding out there were genetic concerns for her baby was both challenging and devastating:

> “…the next day, is when the doctor gave us the information of ‘I think your baby has trisomy 16 or 13’…and he explained it to us and it was scary, like really scary to know that and just like unbelievable and scary and so many thing went through my head, you know, I was emotional, I was crying, and everything was, ‘no this can’t happen’ you know…”

Renee identified the overwhelming feeling of fear and the unexpected nature of this painful and challenging experience.

Associated with a *challenging birth,* Diana labeled her experiences with an extensive labor*:*

> *"*a midwife that was on call, she came in and said that she had talked to a high-risk specialist doctor in Phoenix. And she told him the situation with me and he suggested they just induce me, because I was already dilated at 4 cm, and now I went up to between 6 and 7 cm by Sunday."

Diana's pregnancy, like all three of the Navajo mothers with preterm infants, was high risk and closely monitored by physicians. Diana described an instance with the nurses and doctors being worried and remembered the doctor saying, "…that there was going to be a risk of infection for the baby if she just stayed in longer." For Diana, the birth was even more challenging directly after. She reflected on this event and what the midwife was telling her:

> *"*...her oxygen started going down so they had to take her and at the same time I was taken into the [operating room] because the midwife said I was losing too much blood and she couldn't find where I was bleeding from."

After this event, Diana reported feelings of confusion, sharing: "I just remember waking up in another room." After surgery, Diana woke up to realize "…I ended up getting a blood transfusion, because the midwife told me that I lost 50% of my blood volume." For Diana, this birth experience had the potential to take her life. She reflected on this, indicating that the midwife said, "…if I wouldn't have gotten the blood transfusion that I would've bled out on the table." At the end of this part of her story, Diana identified the uniqueness of her challenging experience was associated with the main theme of perinatal challenges, and she reflected that, "I had never experienced anything like this with my other two pregnancies."

Cori also had experiences associated with a *challenging birth*. Cori also remembered what it was like to have a high-risk pregnancy and to give birth to a premature infant:

> "My blood pressure was sky high and I was in danger of having a stroke so they admitted me into the maternity ward where I was hooked up to medications… June 15th I started to feel my contractions about 1:30 am but they weren't that painful they just felt like menstrual cramps. My aunt arrived at 7:30 am when the contractions started to pick up, the doctor came in at 3:30 pm and popped my water and that's when things really got going. At about 5:45 pm I felt like pushing and the midwife came in and at 5:59 pm just one minute shy of 6:00 pm my son was born at just 4 pounds, 13 ounces."

Here, Cori remembers the experience of being in danger and needing medication to keep her from having a stroke. Cori had a challenging birth due to her own health prior to her infant being born, however, her contractions and labor were reflected on with ease, indicating that overall, the experience was not as distressing for her.

Due to the complicated needs of her pregnancy, Renee had to give birth via cesarean section, which she reflected on and associated with a challenging birth here:

> "I had this birth plan like I'm gonna have him natural and everything, and here all this turns around and then he was still breached when they had done the ultrasounds just the day before. They told me…'we're not gonna wait till you're 38 weeks because once you're 38 weeks your baby is still probably not gonna grow as much, so once you're on

> day, starting the first week, starting the 37th week, the first day of it, is when we plan on inducing you and you're gonna have the baby.'"

Renee identified that the shift in her plans and the unexpectedness of her situation was challenging. For many women, having a birth plan creates a way to cope with the trials of pregnancy, and for Renee, this plan was quickly changed, causing feelings of distress. Renee identified different pieces of this birth experience that stood out for her. She remembered what it was like in that exact moment and could remember details that stuck with her:

> "…my mind and everything is everywhere and I'm like, 'oh my God' and so I told my husband to hold my hand and he held my hand and just the warmth of his hand completely, completely, like just calmed me down and then it took them like maybe a few minutes and that's when we heard the baby cry and I was like oh my gosh and that's when they're like 'it's a boy' and I'm like 'oh' and then they're like 'it's a girl' and I started crying and like yes the baby's here and they're like 'it's a boy!'"

This experience for Renee was one of many sensations: the sensation of feeling cold and scared, the sensation of her mind running, and the need for her husband's comfort. All of these memories played into what was a very challenging and emotional perinatal experience prior to the NICU stay.

The NICU Experience

This theme defines the experiences that mothers have in the Neonatal Intensive Care Unit, including medical needs for their children, how they had to care for or learn to care for a high-risk infant in the NICU and when transitioning back home, the interactions the mothers had with NICU staff, and how they were able to access the NICU services when coming from long distances and balancing other children, work, family, or financial needs

Associated with *perceptions of medical interventions,* Diana discussed what it was like to be with her baby surrounded by NICU technology and life-saving machines:

> "I think the only thing that's kinda hard about it is all the cords and everything from the machine that has to be hooked onto her."

Diana identified that seeing "all the cords" was challenging for her, as it impacted both her ability to interact with her baby and to see her baby in this context. Diana was also able to describe her perception of realizing what needed to be done for her baby in the NICU and what she needed to do to facilitate the necessary medical interventions with the staff. Diana remembered she would "…feed her only at the times…that the schedule that they had her on. I would have to let the nurses know about her wet diapers and um the staff were really helpful when I would try to breast feed her, like when I would try to get her to latch on." Diana also shared some surprise in realizing that she also had to assist with oxygen and shared that "Even the o2, oxygen probes they have on, they have you change that and just like they try to have you involved in your child's care while in the nursery."

When addressing the NICU experience, the other mothers identified experiences that impacted their well-being in mostly negative ways, but Cori identified more positive experiences, particularly in relation to her *perception of medical interventions* for her baby:

> "Every milestone that my son passed made me extremely happy and excited because it meant that he was that must closer to being discharged from the nursery."

Cori identified parts of her experience that were necessary, including that her baby was born premature and had to be cared for in the NICU. However, she also identified that the necessary treatments for her baby were also positive and identified the excitement that came from knowing he would transition home. Cori remembers her NICU experience as being easy and not challenging. She reflects that, “Nothing difficult ever happened while my son was in the special care nursery.” Even within these positive experiences, she is still able to know that this was a unique experience to navigate and identified times in which things were new to her. She remembers, “…they [NICU staff] helped me feed him and do sponge baths even if it was second nature to me but he was just so small.”

For Renee, her baby had complicated medical needs, and her *perception of medical interventions* was identified as a crucial part of her NICU experience. Renee reflected on what it was like to give birth and immediately have her baby taken to the NICU:

> “It was pretty hard, and not able to ever actually hold your baby…right after birth and he has to go up in the NICU and leave you and I was like ‘oh my gosh I can’t believe I just you know did that and went through all that’…”

Renee perceived the reality of having a complicated birth and having her baby taken immediately to the NICU as very challenging. She identified that not having the opportunity to hold her baby was additionally painful after having given birth in a way she did not expect. Renee identified the NICU environment as a part of her experience, and remembered, “He was in a little incubator, so tiny…” Additionally, Renee reflected on discovering her baby would need heart surgery directly after birth. She shared, “…we need to get that fixed, we need to do the surgery, and it’s called a malrotation rotation surgery.”

For Renee, her baby's complicated medical needs created a unique perception compared to other two mothers. Renee perceived her involvement to be overwhelming and at times, very hard. She remembers, "So I had to get used to feeding him with his g-tube and just giving him a bath…was still kind of hard because he was really so tiny… I had to get used to doing all of that myself and I'm glad I learned in the hospital, you know." Here, Renee identified she was alone, due to her husband needing to work. From that, she also identified that learning these new skills in the hospital and with hospital staff, made learning things alone easier for her.

Furthermore, Renee perceived the necessity of her baby's medical interventions as crucial, but also impactful on her well-being. She shared, "and then he had to do the breathing treatments with the, what is that thing called, the nebulizer…they [NICU staff] wanted him to do like little stretches and physical therapy and stuff like that so then it was just a lot there that day, that I had to take on for him because he is born really small." Ultimately, Renee and her baby transitioned home, but this too required Renee to balance feelings of relief with the feeling of being overwhelmed. She shared, "…but he finally got to go home within a week on oxygen so, knowing that he had to go home on oxygen and having to carry another bag with me it was like his feeding bag and then having to carry another oxygen bag with me…"

Diana's reflected on her memories associated with *helpful clinical staff* within the NICU and fondly remembers her experience:

> "I think that's most memorable thing for me from being in the NICU: that bond that some of the nurses get with the kids there."

From Diana's memories, the NICU staff were helpful and kind, and made the situation less stressful for her. She identified that the staff were helpful and "there we just had someone looking over us." Like her quote from above, Diana described that the nurses were also helpful due to the relationship the nurses had with her and her partner as well as their baby. Diana shared that "they tried to make the parents feel as comfortable there", and the nurses "…grew attached to her [the baby]." Diana further described the clinical staffs' demeanor and attitude, sharing that "…how they talk to her and how they care for her and it was just nice seeing that." Overall, Diana felt positive about her interactions with staff, and that, "all the staff were, they were really nice…we never had a negative situation with any of them. They were all welcoming and they would always ask if we needed anything."

Cori also identified her interactions with *helpful clinical staff* in the NICU:

> "All the staff was very helpful and accommodating especially since they knew I was from about 100 miles out of town and had to rent a hotel room for the duration of Caleb's stay in the nursery."

Cori reflected on her relationships with the NICU staff, identifying their ability to meet her needs, but also their ability to understand the context of her life and her experiences with rurality. Furthermore, she was able to identify that for her, having the staff understand she was coming from far away and was out of her element, was an important part of her experience. For Cori, having an emotional connection and the ability to be vulnerable with the staff, were also pieces that she saw as helpful. Cori reflected that, "They [NICU staff] even lent me their ears for when I needed to cry because I missed my daughter so much that I would cry my heart out till I had no more tears."

Renee's experiences in the NICU were challenging, but she was also able to find reprieve in the interactions with *helpful clinical staff.* Renee remembered:

> “...and that’s when they [NICU staff] would call and say ‘you know he’s crying you guys want to come in and talk to him and hold him’, but they were really good on doing their part and taking care of him and we could hold him and they would tell us…that was really good. I really appreciate their time and their efforts and helping us in that way.”

Renee identified that the NICU staff were helpful by letting she and her husband know when the baby needed them. For Renee, being separated from her baby was hard, so having a staff member informing her of when she could hold her baby was impactful. Additionally, Renee identified that vulnerable interactions with the NICU staff was also a way they were helpful. She remembered, “You know, holding your baby and crying and saying ‘I’m sorry I don’t know what happened’ and yeah. It’s just a lot to go through, but I’m glad they were there to help us through that and if I needed anybody to talk to they would say ‘we have a counselor here you can talk to’…” Furthermore, Renee identified that NICU staff directing her to resources regarding her mental health was also helpful.

Diana had experiences associated with *reductions of barriers to care*, and identified ways in which the NICU provided accessible ways to take care of her baby, particularly through the use of a place to stay:

> “…the good thing about…having a relative in the hospital in Flagstaff, they offer a room at a place called the Taylor House… so, it was good, that’s what I liked it. The hospital offers that for the family of patients in the ICU, in the nursery.”

For Diana, the use of the Taylor House, a home where families in the hospital can stay while their infants are in the nursery, made it easy for her to visit and care for her baby while she was away from home. Renee also reflected on how her experience was more accessible thanks to living accommodations associated with *reduction of barriers to care*:

> "…we did get to stay there where the special care nursery is and just on the side of the building, they have like the little rooms where I guess parents can stay so."

Here, Renee identified that being able to stay in a family room by the nursery made it easier to be with her baby. As a mother who reflected that not being with her baby was hard, this was a positive accommodation. Renee also eventually moved to the Taylor House, and identified having a more permanent living space is often helpful for mothers who are dealing with being away from home. Similar to Diana, Renee found the Taylor House helpful when caring for her infant, indicating "…and then they [NICU staff] did call us from there that baby is feeling a bit…and he wants to see you guys and they would still call us from there and it was still really good that we got to stay just across the street in the Taylor House." Additionally, Cori felt thankful for the family rooms on the NICU floor and identified the rooms as an accessible way to see her son, stating, "Even opening up the family room for me to sleep there and be with my baby more." Cori saw the rooms as something the NICU was able to provide that helped in an already challenging situation.

All three mothers described having minimal financial burden associated with visiting and caring for their baby in the NICU. Diana in particular indicated that she "…didn't have to pay anything, everything was taken care of through the hospital, so it was pretty easy getting around." Cori was also identified a lack of financial burden due her experiences with family support which were associated with *reduction of barriers to care.* When asked if there was any burden, she replied*:*

> “Not really, various family members came together and helped me with my car payments and different bills so I had the money to pay for my weekly rates in the hotels.”

Cori was able to identify that, for her, having family assistance was a way to reduce any barriers to receiving care at the NICU. By having her family to support her financially, she was able to spend time away from home and be with her son. Renee identified a lack of financial burdens due to the Taylor house and other nursery accommodations being free, sharing, “…so I mean financially they didn’t ask um for any you know to stay there they didn’t ask for money or anything or any cards to stay there so that was really helpful.”

Perinatal Resiliency

This theme defines how the mothers were able to overcome and cope with challenging circumstances during the perinatal period including pregnancy, birth, and caring for their infant in a Neonatal Intensive Care Unit. This theme includes the intersection of resiliency with important cultural practices and beliefs, emotional vulnerability, mothers supporting other mothers, and the ongoing pandemic and its impact on mothers’ families and health care.

Ultimately each mom demonstrated resiliency during their perinatal journey. Each mother individually tapped into their internal sources of strength, while also seeking out their family and community during adverse experiences. More saliently, cultural resiliency was practiced and valued by each mother. Diana shared experiences associated with *cultural resiliency* when discussing what needed to be done for her baby’s well-being:

> “In my family we’re very traditional, so whenever there is a loved one in the hospital or something’s wrong, we always pray and have like a small ceremony. After her second

> week in the NICU we came home back to the reservation to have a ceremony done for her."

Here, Diana discussed a form of balance: using Western medicine and her family's traditional way of healing. She identified that engaging in a traditional ceremony and prayer were important values within the context of her baby's health by indicating that they went "back to the reservation to have a ceremony done for her." Just like medical interventions, ceremony and prayer were necessary for her baby's life. Diana reflected that, "the good thing about it was like we never stopped praying for our daughter." Diana highly valued prayer and its ability to help her cope and for her baby's health. Outside of balance, Diana identified a form of tension between her culture and life-saving medical interventions. She discussed when she "…was admitted to the hospital in Flagstaff, they asked me like if anything were to happen, I would be willing to get a blood transfusion, and I said no because it goes against my tradition." Later she recalls, "I just remember waking up in another room and in my culture we're, we're not supposed to take another organ from somebody else or get blood transfusions and stuff like that… so, but I ended up getting a blood transfusion, because the midwife told me that I lost 50% of my blood volume." Diana had told the medical staff that she did not want a blood transfusion if it came down to that, however, the midwife told her, "…if I wouldn't have gotten the blood transfusion that I would've bled out on the table." Diana reflected on this experience and this tension and shared that, "…I was just glad that they did it because like…if they didn't then I wouldn't be here." When interviewing Diana, she paused for a very long time after this statement, indicating this was a potentially emotional experience for her. Diana had to hold both her cultural beliefs and her gratitude for being alive. It might be that holding both her culture and things she cannot control is a part of her identity as a Navajo woman. At one point, Diana identified how her Navajo identity intersected with being in the NICU, sharing, “I think being Native American and having to go through that, it has pros and cons that go with it.” Near the end of her interview, however, Diana slightly changed this reflection, indicating that, “I don’t think there’s really any cons that could go with having a, with being Native American and having a baby that is in the nursery.” Here, the subtle shift in first identifying “cons”, but then removing them, may be cultural resilience at play.

Cori was able to engage in *cultural resiliency* and had two different reflections on cultural practices that guided her through this perinatal journey. When discussing her pregnancy, Cori shared:

> “I followed my traditional beliefs to the T. Never did or ate anything which I wasn’t supposed to.”

Here, Cori is identifying cultural practices as something that she consistently followed, even though her pregnancy was challenging and unpredictable. She was able to guide her experience through her traditional ways of knowing. While the two other mothers discussed prayer or ceremony, for Cori it was more about being able to follow rules and norms that she knew would support her health and well-being. Additionally, Cori identified cultural practices as a way to approach infertility and conception. Even prior to her pregnancy story, Cori remembered that after the accident while horseback riding, she tried many different things, and stated, “The doctors just told me that there was nothing wrong with me and to just take [prenatal vitamins] to raise my hormone levels, but that didn’t work so I sought out tribal healing which came in the form of a traditional Hopi chiropractor who fixed me then told me that it would be really difficult to conceive because I had twisted or stretched my uterus.” In this part of her story, Cori is identifying her ability to turn toward her culture when Western medicine did not help her in the way she needed.

For Renee, finding out her baby may have genetic concerns was an unexpected and emotional experience. She remembers part of her experience associated with *cultural resiliency*, and how she and her husband also found ways of healing:

> "He's like we can get a prayer done for baby for him to be okay… so I was like ok, so we got let go that Friday, we came back into [hometown], and we got a little, we got a prayer done for the baby."

Renee's husband sought out cultural practices to comfort Renee and both Renee and her husband saw prayer as a form of well-being for their baby and family, which was similar to Diana. At this point in their pregnancy, the doctor was very concerned about the baby's well-being, and when the parents shared they were going back to the Navajo Nation to get a prayer done, Renee remembered, "…and the doctors wanted us to stay there until I was at least 37 or 38 weeks, for the baby's lungs to be like mature enough to be strong…but I really fought against it and I was like well, and they [doctor] were like, 'we want you to stay here to keep an eye on you'… and he [doctor] goes, 'so if you leave it's gonna be on you and you'll be on your own, we just want you to stay here to keep an eye on you, but if anything comes up over the weekend, you know, come back Monday, and once you come back Monday we're gonna keep you in the hospital.'" Renee identified points of tension between her cultural beliefs and the doctor's wishes. She reflected that she "fought against it", even though her baby's health was at stake. Renee identified that choosing to leave despite the doctor's wishes indicated how much she valued her cultural practices as a way of healing. Furthermore, the doctor's inability to hold this tension like Renee, and sharing that Renee would be on her own if she left the hospital, may highlight an inability for some medical providers to understand another's cultural beliefs, and to hold those cultural beliefs as additional forms of healing and healthcare. Ultimately, Renee and her husband found healing and resiliency from their medicine man. She shared, "…we got a prayer done for baby and medicine man said it was gonna be ok, it's gonna be ok, you know, just stay strong, stay strong and be there for baby."

When exploring emotional vulnerability, each mother had the ability to engage in the intensity and impact of their emotions during their perinatal experience. Diana shared experiences associated with *emotional vulnerability*, and being open about her emotional experiences in all parts of her story, including the story of her pregnancy, birth, and the NICU stay:

> "…even to this day…it still scares me, like, I couldn't, I can't imagine my kids not having me there."

Here, Diana reflected on the fear that was associated with her blood transfusion and being vulnerable about what could have been if she had died. For Diana, this emotional experience held great reflection for her. She identified the intersection of a potentially tragic experience with her family and life and what held meaning for her. Diana also expressed feelings of guilt associated with being at the NICU while her family was far way, sharing, "considering that I have two other kids, it was hard trying to, at the beginning, that first week, I had a lot of guilt." Overall, Diana shared the intensity of having her baby in the NICU, sharing, "I felt like, I needed to be there with her all the time, and it just made me cry."

Cori also displayed signs of *emotional vulnerability* uniquely compared to the other mothers. Here is a significant reflection of Cori near the end of her narrative:

> "For the future I hope my son has a very long and healthy life. I wish that his father and his family come to except my son and build a relationship with him. If not I am fine with it and just happy that I have a healthy baby boy."

Here, Cori is identifying that an important piece of she and her son's well-being is the connection that she and her son can have with his family and community. Cori's vulnerability in this statement is sharing the idea that her son and is father may not have the relationship that she wishes for, and to long and to wish for this is her way of expressing what this means for her. She ultimately identified further resilience by engaging in acceptance and sharing her gratitude for what is. Cori also identified points in her NICU stay where she felt an overwhelming amount of emotion related to not being with her older daughter, sharing, "They [NICU staff] even lent me their ears for when I needed to cry because I missed my daughter so much that I would cry my heart out till I had no more tears."

Renee identified many points in her perinatal journey that were *emotionally vulnerable.* During the NICU stay, Renee remembered how emotionally impactful the experience was:

> "I would say it is a lot to go through, it's a lot to take in sometimes and sometimes you just really feel like breaking down and crying and while you're holding your baby and sometimes I did do that."

Renee identified and had the ability to look back on the emotions she felt during that time. She indicated it was "a lot to go through" and "a lot to take in." Additionally, she had the ability to reflect on how it impacted her and how it would cause her to break down. Furthermore, Renee identified that her emotional vulnerability at this time was intensified when she was holding her baby, highlighting the attunement and attachment which intensified the emotional experience. Additionally, Renee engaged in emotional vulnerability by identifying thoughts and processes that occurred for her during this time, identifying points of anxiety related to her baby's well-being. She remembered, "…but it does give you some time, like, 'why does my child have to go through this,' and you know just questions that you have on your own that happen in your own mind I guess."

Maternal empowerment was explored and shared among all three mothers. While Diana was able to be vulnerable in her reflections, she also engaged in *maternal empowerment*, by asking her mother and sister for support and advice as she went through her pregnancy, birth, and the NICU stay:

> "…and, they all told me the same thing, that it's only temporary that my daughters gonna be there. It is good that I was spending time with my other kids because they missed me too and…just be strong."

Diana reflected here that the other women in her life told her to "be strong" and identified this advice as a way to cope and sought strength for herself by confiding in them.

Cori was someone who never thought she was going to be a mother of a child she gave birth to, so when her pregnancy was a surprise, she was able to reflect on experiences of *maternal empowerment*:

> "I was excited to be a mother because I got plenty of practice with my siblings and I was always babysitting for my aunts and of course my daughter was the first child I took care of on my own even though it was after 6 weeks."

Cori identified interactions with maternal figures in her life that led to feeling confident in being a mother. She can identify points in her history that informed her beliefs about her identity as a mother in the present. Additionally, Cori found support in other women during her birth even though her mother could not be there. She remembers, "But my mom having COVID wasn't able to be with me so we called one of my Aunts who agreed to be with me, June 15th I started to feel my contractions about 130am but they weren't that painful they just felt like menstrual cramps. My aunt arrived at 730am when the contractions started to pick up…Cori's mother and aunt came up multiple times in her story, and she identified them as people who empower her. Interestingly, Cori also found maternal empowerment in herself. When reflecting on her identity as a mother to her 6 year old adopted daughter, she said, "We were inseparable from the day she [her daughter] came into my life we were always together. She spent every night in my arms that being left without a goodbye and an explanation for why I was being left behind at the hospital was hard on the both of us." She is identifying that being resilient during the NICU experience can also impact her identity as a mother in other contexts, and even cause heartache.

For Renee, another form of resiliency was her ability to be supported women when realized she was delivering via cesarean section, she reflected:

> "…well, me and my sisters delivered. I have an older sister that's older than me and she never had a cesarean or anything so I never knew anything about it and my sister that's a year younger than me, she never had a cesarean so like I didn't want to have a cesarean."

Renee identified that she used family support and experiences to inform her perinatal journey, particularly with pregnancy and childbirth. Renee was able to rely on friends in her community as well. Renee remembers talking to a friend from high school. She stated, "…but I did get in contact with one of my friends. I did tell her about my pregnancy, and when she had her first cesarean she was still in high school, like a senior. We were both seniors and um, she had a cesarean and back then I don't remember asking my friends then like how does it feel, you know, having a cesarean, did it hurt? She goes, oh it didn't hurt it just hurts a little bit after." Here, Renee identified that having a friend to walk her through a cesarean section was helpful. Prior to this, Renee felt fear and surprise at needing a cesarean section, so she relied on friends and family to help her process and cope.

Maternal empowerment is not only asking for advice or soliciting support from significant women in your life, but also the act of supporting other women. Both Diana and Renee chose to end their interviews by sharing a message for other mothers. Diana shared, "I think just like a positive message to other, other mothers that have to go through this similar situation is just to be strong for your little one… it's only temporary and just think about the care that your little one needs, and, don't rush the, the process, your baby will, will adjust on his or her own time." Renee shared, "I just want other mothers out there that go through this and just let them know to be strong, stay strong and be there for your baby, it's gonna be tough but hang in there." Here, both mothers were able to pull from the maternal support they received from the women in their life, and shared it with other women, imparting resilience.

Similarly, each mother utilized their families has primary forms of support and to cope during adversity. Diana discussed how she asked for *support from the family system,* and identified the individuals in her life who she could rely on during her adverse perinatal challenges:

> "I talked about how I felt with my mom, my husband, and my sister."

Within Diana's life, she has individuals that she needs for support, and like many mothers navigating the NICU environment, it is challenging and isolating to do it alone. Having both maternal support from other women, and support from her husband and others in her community, she was able to gain strength collectively.

Cori's family supported her in many different contexts, however one part of her story stood out when she was asked what was memorable about her NICU experience:

> "Watching my baby grow every day and watching my daughter become attached and protective of her new baby brother."

As mentioned earlier when discussing *emotional vulnerability*, Cori often identified connections between her family and even relationships not meant to be, as points of emotional meaning and forms of resilience. Here, Cori identified that having her older daughter develop a loving relationship with her baby was something memorable and watching this unfold was a way to help Cori cope. For Cori, support from the family system means her family fostering and developing meaningful relationships with one another, especially in times of adversity. Additionally, Cori was able reflect that financial support and being there for her in times of need, were ways she and her family fostered resilience. She remembers, "Various family members came together and helped me with my car payments and different bills so I had the money to pay for my weekly rates in the hotels" and "But my mom having COVID wasn't able to be with me so we called one of my Aunts who agreed to be with me."

Additionally, Renee emphasized the role of her husband in her family system during her birth experience. She shared, "and it feels cold in the operating room, so, having the warmth of my husband's hand just completely calmed me down." She identified that outside of her extended family, her husband was a key source of support and coping.

Finally, COVID-19 was a common thread for each mother. Diana reflected on how COVID-19 impacted her perinatal journey:

> "…because umm, even though the hospital is probably like the, uh, one of the safest places, but I just kept thinking umm she's gonna be a newborn and with the whole virus I was scared to, uh, umm, that's just what kept going through my mind. That was, that was why I was scared."

Here, Diana reflected on her emotions that she felt when considering giving birth to her baby during the pandemic. Giving birth to an infant at any point in one's life is a stressful experience, but the intersection of COVID-19 required further resilience and vulnerability to navigate her journey. Diana also identifies how the community further supported her resiliency, by indicating that, "the midwives would still call me to see how I was doing and because with them not allowing patients into the hospital for a little while." Diana was not having a typical perinatal experience and shared that, "It was a lot different, not having to go to the hospital for check-ups." While individually she was able to navigate these odd differences due to COVID-19, her community continued to do what they could.

COVID-19 significantly impacted Cori's family and her birth experience. Cori reflected emotionally what it was like to have COVID-19 disrupt her family system:

> "I was afraid and heartbroken that my mom wouldn't be with me for the birth of my first born. But I was afraid that she wouldn't make it that COVID wouldn't allow her to be a Grandmother and would take her from us before meeting her Grandson."

Cori identified that COVID-19 directly impacted her expectations of becoming a new mother. She went through her pregnancy with the expectation that her mother would be there to support her, and vulnerably shared how “heartbroken” this made her feel. Cori identified a very real and drastic impact of the pandemic: that it would take someone she loved. A thread woven through Cori’s story is the importance of supportive and loving relationships within her family system. For Cori, COVID-19 was a direct threat to her relationships, especially those with her baby.

Unlike the other two mothers, Renee did not emphasize the impact of the pandemic to the same extent. For her, it was something that could get in the way of celebrating with her family, but she found a way to overcome it:

> “…even though we’re in this pandemic, I was thinking we can stay home and have fun as long as we can be home on Halloween.”

Prior to saying this, Renee was reflecting on how they had been in the hospital with their baby around Thanksgiving, Christmas, and New Years Eve. She was identifying that the hospital stay was negatively impactful on spending time with her family, but that for once, they were all together for a holiday: Halloween. Ultimately, Renee identified that since the pandemic was forcing them to stay home, they could still celebrate, showing signs of coping and resilience.

Summary

The findings above explored each mother’s story, and how their stories informed the super-ordinate and sub-themes that emerged from their narratives. The process of “case in theme” (Smith et al., 2012) was used to give agency and voice to each mother, and the smaller number of participants allowed the principal investigator to go more in-depth. Ultimately, all of the above super-ordinate and subthemes emerged due to the impact of the mothers' narratives and the significant extent to which the mothers discussed the above themes in their stories.

I was able to explore Navajo mothers' feelings and thoughts about challenging pregnancy and birth experiences. I was able to discover how they perceived and cared for their infant in the NICU environment and discovered their gratitude for the helpful NICU staff. The most salient discovery, however, was the complexity and emotion that existed in individual mothers' reflections on resiliency. I felt extremely naïve for considering resiliency from such a minimal standpoint in the original proposal of the study. I was merely considering what the impact of stress would be, and how mothers would cope.

When considering the social-ecological context of Navajo women, it must first be viewed through the lens of historical trauma. Historically, Indigenous women's bodies were not valued, and Indigenous women were often sterilized without their consent due to eugenic thinking (Maceika, 2018). Furthermore, Indigenous people continue to have their rights and freedoms limited by the U.S. Government, for example, the U.S. policy of only supporting tribes that are "federally recognized" (Brayboy, 2005). Navajo women today, including the women in my study, have potentially inherited this trauma, and it continues to intersect with the context of poverty, rurality, physical and mental health, with societal perception of Indigenous life and culture, and within the tension Indigenous people may feel while holding their culture and at the same time being systemically devalued by another (Goodkind et al., 2012).

From this lens, Navajo mother's resiliency is not only a salient finding from this study, but also the data that can inform how we, as practitioners, value, understand, and enhance the health and existing strengths within Navajo and other Indigenous mothers (Teufel-Shone et al., 2016). To do this, Navajo mothers' resilience cannot be analyzed through a Eurocentric-Western definition, but one that is social and ecological in nature, and considers their individual and collective cultural processes when faced with adversity (Ungar, 2012). Teufel-Shone et al. (2016) discuss the nature of Indigenous resilience can be both individual and collective. Additionally, Indigenous, and subsequently Navajo resilience, occurs in multiple social ecologies, whether that is in their home, in the community, in the NICU, or in the context of broader health inequities (Teufel-Shone et al., 2016; Ungar, 2012). For the Navajo mothers in my study, their ability to be resilient in the context of preterm birth during the perinatal period, or *perinatal resiliency,* was found to occur both individually and collectively.

Using cultural practices and beliefs was a form of resilience for all three Navajo mothers, which also happened to occur both individually and collectively. Often, the three mothers identified individual emotional reactions to perinatal experiences, such as fear of losing their baby or concerns about baby's health that prompted them to continue to rely upon collective cultural engagement and return to their community of origin. Once home, the mothers worked with traditional healers or participated in ceremonies or prayers that would benefit their baby's health. Additionally, Diana was able to identify individual cultural resilience through the consistent practice of prayer.

In Teufel-Shone and her colleague's (2016) review of studies addressing individual and collective resilience, they identified that cultural engagement for Alaska Native peoples' collective resilience, often meant "…a literal return to home after time spent away…", which I found to perfectly explain Diana and Renee's description of collective cultural resilience, as they were away in the NICU and went home to heal and promote their baby's health (pg. 5). Additionally, Teufel-Shone et al. (2016) discussed lack of research, but also the importance Indigenous adults carry as both caregivers to children and potentially to elders and how they may act as a “cultural bridge” between the two generations (pg. 6). Similarly, I found this to be particularly salient for Diana and Renee, who found themselves in vulnerable situations where they had to balance their cultural identity and knowledge with the knowledge presented to them about their baby’s health from a provider-based system of power and privilege.

Two themes associated with utilizing and engaging with their social networks of family and friends emerged in Diana, Cori, and Renee’s narratives: *maternal empowerment* and *support from the family system*. Both were identified by the mothers as forms of collective resilience, as they described their relationships with friends, other mothers, maternal family figures, and their partners to be impactful on adverse experiences. The Navajo mothers found that talking to family or friends about their similar experiences, or soliciting advice, or being told to “stay strong” were ways they practiced collective resilience in unprecedented scenarios. They also learned from or empowered other mothers through learned experiences. Teufel-Shone et al. (2016) identified resiliency literature that addressed the idea of talking to one another, but also financial support as ways of Indigenous collective resilience, which was particularly identified by Cori in her narrative in accessing her infant’s healthcare.

When originally defending my prospectus two years ago, COVID-19 was not a factor, but in its onset, it completely changed the outcome and procedures of my study, and ultimately become a consistent thread in all three mothers’ narratives. When considering the disproportionate impact COVID-19 had on Navajo communities, it makes sense that the mothers would identify the pandemic as having points of adversity and having intersection with their perinatal journeys. I identified the emergent theme of *COVID-19* as a point of perinatal resilience due to both its individual and collective nature. The mothers reflected on how the pandemic loomed over their pregnancies and births, making them afraid to go to the hospital or making their mothers ill. The mothers described the pandemic as a potential barrier, that ultimately through getting to the birth of their infant, was overcome through their own strength. Collectively, the Navajo Nation put immense effort and intention into protecting their communities through culturally informed public health practices that considered Navajo people in all contexts of their life (Northern Arizona University, 2021). While Diana, Cori, and Renee were navigating the pandemic individually on their perinatal journey, they were being protected and cared for by their community; highlighting that individual and collective resilience have the potential to be intertwined in systems of culture, family, and health.

Brene Brown (2006) shared that the word “vulnerable” comes from “…the Latin word, *vulnerare,* meaning, ‘to wound’.” (pg. 48). *Emotional vulnerability* became an emergent theme for all three Navajo mothers when their ability to reflect, have insight, and connect their experiences to a larger meaning of being a mother was salient in the narratives. Diana, Cori, and Renee were emotionally wounded at many different time points in their perinatal experiences. Diana’s intense resiliency and vulnerability were evident in her reflecting on the pain she felt when she considered the what-ifs of dying, and what that would mean for her family; along with her ability to feel gratitude for living while also knowing receiving a blood transfusion was against her cultural beliefs. In fact, vulnerability was practiced in each step of these mothers’ journeys, including being interviewed by me. To engage in trust and to remember pain interwoven with joy, and then to share those experiences with me, knowing and embracing the fact I would share those experiences with others, is vulnerability in the form of collective resilience.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

This dissertation study was proposed to address the dearth of research available on Indigenous women's experiences with preterm birth, particularly with Navajo women, as these were mothers whom I had direct contact with and had met their infants in the NICU. At the time, two years ago, the Flagstaff Special Care Nursery had mainly Navajo infants in their care, and I wanted to understand the cultural responsiveness of their treatments and interventions, as well as their cultural understanding of Navajo families, given the breadth of research addressing perinatal health inequities for Indigenous women across the country. I realized the lack of research combined with the census of the local NICU having majority Navajo families could lead to potential mistreatment or biases to emerge within clinical interactions. I originally wanted to have data that I could give to perinatal practitioners for that reason: what is this experience like for Navajo mothers, how do Navajo mothers feel about having a preterm infant, what do they perceive their NICU experience to be? I wanted NICU practitioners to know exactly what Navajo mothers were thinking and feeling during this process, so practitioners could be more culturally informed and responsive when a Navajo baby was in their care.

Implications for Practice

Flagstaff Medical Center Special Care Nursery and NICU practices

As the geographical context for this study, the implications from the mothers' stories are most saliently directed toward Flagstaff Medical Center (FMC), the Special Care Nursery (SCN) and the broader context of NICU services. The second research question addressing Navajo mothers' perinatal experiences after giving birth and in the NICU and beyond, can help inform how the FMC SCN supports and provides equitable care to Navajo mothers. When looking at the outcome of the data, the mothers' narratives presented three important sub-themes: how the mothers perceived the NICU interventions, the helpful NICU staff, and how the NICU reduced barriers to care.

NICU interventions in a cultural context.

While Diana, Cori, and Renee reported gratitude and appreciation for their NICU staff, and often highlighted how helpful they were through the process, this was not something I fully expected to find. Particularly when considering NICU practitioners' racial biases and assumptions documented in the literature review toward culturally-linguistically diverse mothers (Birch et al., 2009; Brooks et al., 2016; Gonya et al., 2013; Lilo et al., 2016; Marcotte, 2017; Miquel-Vergas et al., 2011; Roberts et al., 2016).

However, despite what the three Navajo mothers shared, and given the literature, it is safe to assume similar biases and assumptions may be made about Navajo mothers in the Special Care Nursery. When discussing the low show rates of Navajo mothers for NICU follow-up appointments with developmental staff at the Special Care Nursery in Flagstaff over two years ago, my findings provided potential answers to what could be impacting this phenomenon. Stigmatization and assumptions about Indigenous health practices and inability to access care are rampant in both health literature and health settings (Goodman et al., 2017). With the data Diana, Cori, and Renee provided, including their experiences related to poverty, rurality, and use of cultural resiliency, we may be able to generalize to future Navajo mothers in the Special Care Nursery, and what barriers or interactions could create unsafe spaces for their maternal-child health needs.

All three mothers shared that utilizing traditional healers and practices were one of the most important ways to maintain resiliency during their baby's stay in the NICU. However, at least two of the Navajo mothers in this study had to travel hours back to their communities to engage in important cultural practices to promote their baby's health. The Navajo mothers' stories in this study inform the need for institutions like FMC to provide access to traditional healing.

Ways to promote and incorporate traditional practices in the FMC SCN include but are not limited to: FMC SCN providers (i.e., NICU social workers, developmental specialists, etc.) making connections with the Navajo Nation and traditional healers in Navajo communities and creating pathways for traditional healers to be a part of FMC SCN interventions, incorporating traditional Navajo birthing practices into the NICU and training FMC SCN staff on the traditional Navajo values and practices related to maternal-child health to improve the quality of care they provide to Navajo mothers.

Another important cultural consideration is the implementation of midwives in the FMC SCN. Midwives have the efficacy to reduce maternal and neonatal mortality and can improve maternal-child well-being through interventions that place the infant and the mother first, and they can be effective maternal-child health advocates in euro-centric, Western health facilities (Nove et al., 2021). On top of this, midwives, particularly those who are Indigenous, could bridge Indigenous culture and Western healthcare, prepping mothers for their entry into the hospital and being an advocate for when cultural resiliency is necessary for health and well-being for mothers and infants within these settings (Theobald, 2020). The use of midwives in institutions like FMC SCN, and promoting policy to support the funding and training of midwives in these settings, could be culturally beneficial for mothers who are disproportionately impacted by adverse birth outcomes.

NICU medical interventions, such as kangaroo care (Gonya & Nelin, 2012), can only be truly equitable when provided in a cultural context for the mothers that access the prenatal and perinatal care at the FMC SCN. It is the responsibility of NICU providers to have insight into this cultural context and foundation to better serve and support mothers like the ones in this study. It is possible for institutions like FMC to be a facilitator of both traditional and Western medicine, rather than creating an impetus for Indigenous mothers to leave the hospital to access cultural practices.

Increasing access to NICU follow-up services.

The mothers in this study described an increased access to care due to the ability to stay at the NICU with their baby through the Taylor house, the family rooms, and local hotels. The FMC SCN is actively reducing barriers to NICU interventions by providing these accommodations for free. An important take-away for FMC SCN staff and leadership is the importance of these accommodations, and their potential value in a broader context of perinatal and developmental care. Babies born prematurely are at risk for developmental concerns, and therefore need follow-up care after their NICU stay (McGowan & Vohr, 2019). NICU providers often speak to the inability to engage mothers in developmental follow-up after a family's NICU stay (Roberts et al., 2016). When considering the context of Navajo mothers' lives, including the intersection of rurality and poverty, rural-serving institutions like FMC may be the key to improving access to necessary follow-up care.

All three mothers in this study lived hours away from FMC and from FMC developmental services, which is often the case for many Navajo mothers. To continue to reduce barriers, FMC SCN may want to consider the expansion of its living accommodations to support a higher number of mothers, but also to expand the accommodation's usage to a broader context, including post-NICU developmental services. For example, allowing mothers to stay overnight when utilizing developmental services, or providing financial support (i.e., grants, vouchers, waivers, etc.) for local hotels in the Flagstaff area when mothers are traveling from far distances for developmental services.

When considering this from an early intervention standpoint, the FMC SCN is one of the first relationships that Navajo mothers have with developmental providers. If FMC SCN staff can provide NICU care in a traditional Navajo context, this could create more sustainable relationships between the FMC SCN, FMC development care and pediatrics, and Navajo mothers they serve. As a rural-serving medical center, FMC and other similar institutions are key players in providing equitable healthcare and creating safe spaces for Indigenous women to care for their infants. The Navajo mothers' stories are data from which FMC can support Indigenous resilience in the context of maternal and child health.

Supporting Maternal-Child Health on the Navajo Nation

Diana, Cori, and Renee all lived on the Navajo Nation for the duration of this study. All three mothers' narratives described instances of community care and support, including support from family, friends, and traditional healers. While each mother had unique experiences when engaging with their community to access healing and collective resilience, these experiences can be applied to a broader context of maternal-child public health initiatives on the Navajo Nation and through Navajo organizations pertaining to maternal-child healthcare.

Maternal empowerment and peer support.

At least two of the mothers in this study wanted to give a message to other mothers: stay strong for your baby and you will get through this. I found this to be particularly salient, and in the bigger picture of all three mothers choosing to share their story, I realized there is the potential for sustainable and long-lasting healing from perinatal trauma associated with NICU experiences when Navajo mothers support one another. When applied to supporting maternal-child health, the Navajo Nation may be able to utilize significant organizations (i.e., Department of Health, Women, Infants, and Children, Growing in Beauty, etc.) to promote collective resilience for mother who give birth to preterm infants. These organizations may be able to facilitate peer support groups or even train parents of premature infants to engage in collective cultural support for new mothers of premature infants. This may come in the form of mothers becoming cultural liaisons to other mothers in institutions like FMC, or Navajo organizations providing the space and resources for mothers to come together to share in their experiences with the NICU and prematurity.

Case management for mothers of premature infants.

As discussed previously and discussed by one of the Navajo mothers in this study, the use of midwives can be a great source of support for Navajo mothers of premature infants. Due to Northern Arizona and the Navajo Nation’s rural nature, there are limited options and medical facilities for Navajo mothers with high-risk pregnancies. Only one NICU, the Flagstaff Medical Center Special Care Nursery, can support more high-risk mothers and infants, while Tuba City’s NICU may not. Furthermore, having limited options for medical facilities means Navajo mothers also have limited ability to advocate for quality care for themselves and their babies. If possible, the creation or implementation of a program on the Navajo Nation that connects Navajo midwives with Navajo mothers who have high-risk or preterm births, could be a way to promote equitable healthcare in Western institutions like FMC. Ideally, Navajo mothers could have a midwife for support through the trauma of the NICU, for obtaining important traditional knowledge related to maternal-child health, and they could have an advocate in settings where they may be target to racial bias and inequitable perinatal care.

The Navajo mothers in this study saw their communities on the Navajo Nation as safe spaces of healing and collective resilience that informed their individual resilience during their NICU experiences. Each mother was able to find resources due to the strength of their communities and their relationships with friends and family. Their individual abilities to do this is a reflection of Navajo maternal strength as a whole, and points to what the collective strength of the Navajo Nation and its leadership can do to further promote mothers' experiences within maternal-child health.

Implications for health psychologists

As discussed in the introduction, Gurung (2019) places health psychology into three categories: "stress and coping, health behaviors, and issues in health care" (p. 22), and they describes the role of a health psychologist as facilitating the intersection and significance of these categories. As a future health psychologist, particularly in the field of maternal-child health for rural and Indigenous families, my study taught me that we can sustainably support mothers' resilience and strength by utilizing women's' stories as evidenced-based data for psychological interventions.

Teufel-Shone et al. (2016) discusses the plethora of public health research merely pointing out negative health outcomes and functioning from a deficit model of health for Indigenous people and argues for research focusing on individual and community strengths that "…could inform discourses of AIAN health as well as the creation and implementation of programs and policies intended to improve health outcomes with this population." (pg. 6). My goal has changed from wanting to provide perinatal clinicians with Navajo mothers' lived experiences to inform culturally responsive interventions, to also wanting to provide data showing clinicians how Navajo mothers and their communities function under stress and adversity to overcome systemic inequities.

Ultimately, health psychologist in Indigenous-serving and rural-serving institutions can potentially focus more of their energy and efforts on promoting and integrating current practices related to healthcare and healing in the form of Indigenous resilience. Additionally, healthy psychologists within rural and Indigenous-serving healthcare settings can provide interdisciplinary education to other maternal-child health providers in the hopes that they too can promote Indigenous resilience in the NICU and beyond.

Implications for Policy and Maternal-Child Public Health Efforts

Not only can Navajo mothers' stories provide data for how individual institutions and organizations can promote equitable health and maternal-child well-being, but these stories can inform a greater need for long-lasting and sustainable policy for Indigenous women's health. When considering Navajo mothers of premature infants in the context of the rural Southwest, below are possible solutions to promote maternal-child health policy and public health initiatives for Navajo mothers on and off the Navajo Nation.

Cross-institutional collaboration.

When considering the implications for NICU's such as the Flagstaff Medical Center Special Care Nursery and for maternal-child health organizations on the Navajo Nation, these efforts will require collaboration between institutions to be sustainable. While organizations on and off the Navajo Nation can individually impact the quality of care for Navajo mothers through facilitating cultural practices and resilience, the context of rurality and poverty create an impetus for these institutions to work together. The need for collaboration also creates a need for policy change for rural-serving health care settings. These changes would include necessary funding, resources, and support for collaborative teams and providers to work together on important maternal-child healthcare outcomes for Navajo women and children. At this time, the Navajo mothers in this study shared experiences that show a gap between how they access services in the NICU and how they obtain support from their community, yet both of these go hand in hand.

Rurality, poverty, and healthcare.

When considering the intersection of poverty and rurality, Diana, Cori, and Renee found that it played a part in their perinatal experience. In particular, their experience with giving birth off the Navajo nation, which caused them to expend financial resources when living on household incomes of $40,000 to less than $20,000 per year, and sacrifice time with their families. As discussed previously, Northern Arizona and the Navajo Nation's rural nature create limited perinatal healthcare options for Navajo mothers with high-risk pregnancies.

Only one NICU, the Flagstaff Medical Center Special Care Nursery, can support more high-risk mothers and infants, while Tuba City's NICU may not. Furthermore, having limited options for medical facilities means Navajo mothers also have limited ability to advocate for quality care for themselves and their babies, and they are not alone. Thorsen et al. (2021) further supports Diana, Cori, and Renee's experiences through the evaluation of disparities in access to obstetric services for Indigenous women in Montana and found limited access to higher-level specialty obstetric care in rural areas, particularly for mothers with high-risk pregnancies and those who had financial burdens or were uninsured. Indigenous women who lived on reservation land had disproportionate access to obstetric care than Indigenous women who did not.

Additionally, Probst et al. (2004) found that 92% of counties in the country that have an Indigenous majority are considered health professional shortage areas and Von Reichert et al. (1995) found that 37% of Indigenous women were more likely than white women (19%) to give birth in a county other than their home county. Having limited access to necessary perinatal care with a high-risk pregnancy, along with facing barriers related to poverty and rurality point to the need to evaluate Navajo women's access to care in the context of policy and legislation, given that only recently did congress address the need to identify rural areas with healthcare professional shortages to recruit professionals to these areas (U.S. Congress, 2018).

Early intervention and early childhood development.

As a researcher and practitioner in the field of early childhood and early intervention, I developed an interest in infants and toddlers who were cared for in NICUs and their subsequent follow-up care. Follow-up development care and monitoring is delicate, as babies with traumatic birth histories and complex medical conditions are often diagnosed with developmental disabilities and atypical neurodevelopmental outcomes (McGowan & Vohr, 2019). Parents work in conjunction with early intervention providers to determine the needs and outcomes for their children, and often rely on providers for important clinical decision-making and advice (Khetani et al., 2017). I had the realization when connecting NICU babies to their follow-up care, that early intervention truly starts in the NICU, and not after the baby is taken home. Navajo mothers' first exposure to future health implications and needs for their infant is in the NICU. Any negative or harmful experiences they perceive from NICU staff towards them, or their infant may impact how Navajo mothers' gauge future interactions with early intervention providers.

Additionally, when considering racial bias in the NICU and early intervention settings, there is an impetus for addressing changes within perinatal and early intervention policy that focuses on training early intervention providers to engage in cultural understanding and utilize Indigenous community-based supports to provide Navajo mothers with what they need to support their children in the context of preterm birth. Furthermore, having cultural liaisons or culturally responsive midwives that can help bridge Navajo women with the clinical culture of the NICU could be beneficial in preventing ruptures in parent-practitioner relationships. Any training efforts for early intervention providers or midwives would need to be funded and supported through state and federal entities. Therefore, the data from this study can be used to inform the need for maternal-child health policy changes that address the need for culturally informed training and the teaching of traditional practices to providers that interact with Navajo mothers with high-risk pregnancies and premature infants.

Summary

I went into this research with the goal of exploring learned experiences, only with knowledge of perinatal disparities Navajo mothers face. I concluded this research by realizing I wanted to give agency to the three Navajo mothers' voices by highlighting their instances of strength in the shadow of inequity. Brayboy (2005), through the lens of Tribal Critical Race Theory (TribalCrit), taught me that "…for many Indigenous people, stories serve as the basis for how [Indigenous] communities work." (pg. 427). He implies that "theories, through stories and other media, are roadmaps for our communities and reminders of our individual responsibilities to the survival of our communities" (pg. 427). When considering this within Diana, Cori, and Renee's experiences, their stories regarding their NICU experiences serve as frameworks through which future health intervention, promotion, and policy around Navajo health inequities can be informed. Through this theory, Navajo mothers' sharing their stories lend to their ability to support their communities, to promote policy, and to create change in the face of adversity due to systemic oppression within spaces of health

CHAPTER 6

CONCLUSION

The findings of this study directly inform researchers, clinicians, or medical staff who work with Navajo mothers and their preterm infants, as it provides Navajo mothers' experiences when giving birth to and caring for a preterm infant, which continues to remain undocumented in the research and literature. From 2014 to 2019, the percentage of preterm birth rates by race/ethnicity has gone from 9.5% to 10.7% for Indigenous mothers in the state of Arizona. Meanwhile, the same rate for white mothers in Arizona during 2014 to 2019 increased from 8.6% to 8.7% (March of Dimes, 2021). On the Navajo Nation, between 2016 and 2017, the rate of preterm birth in Navajo women increased from 10% to 11%, and in the nation overall within this same time period, the preterm birth rate has increased from 11% to 12% (Navajo Nation Maternal and Child Health Needs Assessment, 2020). This information highlights both the imperative need for better understanding of this phenomenon for Indigenous women, and the disparate nature of these health statistics. Since finishing the literature review for this study two years ago, the impetus for the findings of this research remains the same: to inform the practice and interventions created by clinical and medical practitioners who work in the field of maternal-child health. Furthermore, as stated in the discussion, Diana, Cori, and Renee's stories lend to a broader context of perinatal health research, where Navajo resiliency and narratives are utilized as frameworks for sustainable health outcomes.

Limitations

Although Smith et al. (2009) discuss the need for smaller sample sizes, ideally three to five, for those doing theses or dissertation research, I had planned to obtain at least 5 participants overall. When first proposing the research in 2018, the Flagstaff Medical Center Special Care

Nursery Census was fairly high, with almost 10 Navajo infants in the NICU at once. However, after the onset of COVID-19 in the Spring of 2020 prior to my data collection, the Navajo Nation was disproportionately impacted by the pandemic, resulting in nation-wide shutdowns and community isolation. These factors, along with further isolation for myself and Navajo communities outside of the Navajo nation, I found it difficult to recruit mothers for my study. Multiple efforts and attempts were made to recruit Navajo mothers, with very little response.

Another limitation of the study is being unable to reach data saturation. The use of a written narrative for Cori, compared to obtaining spoken interview narratives from the other two participants, created a lack of robust information. Cori described a situation where she did not have reliable internet or cell service due to where she lived on the Navajo Nation, but emphatically wanted to provide her story. I chose to include her narrative, after a required IRB amendment, due to the limited number of participants. The limitations this caused were being unable to analyze linguistic data (i.e., sound of voice, pauses, emotion, etc.), having a shorter narrative than the other mothers, and being unable to get a hold of her for further follow-up prompts or questions. Therefore, Cori's narrative was somewhat limited compared to the other mothers.

Finally, a significant limitation of this study is related to the challenges of cross-cultural research. As a white researcher and clinician, I understand that I come from and ultimately benefit from systems of power and privilege. It is a possible limitation that the Navajo mothers who participated in this study did not feel safe or comfortable sharing all aspects of their prenatal and perinatal experiences. Additionally, I had to ensure the participants' interviews were both equitable and safe, and to provide accurate reflections and representations of the mothers' narratives. From this, I engaged in a learning process that allowed me to discover further limitations. By conducting the interviews myself, as a white woman, and by only conducting one interview, my presence and the lack of time may have inhibited my ability to create a safe space.

Implications for Future Research

Although I thoroughly enjoyed and was passionate about my research and the findings that resulted, the COVID-19 pandemic created a significant barrier in conducting the research and collecting participants. My initial hope was to visit the mothers in their homes or place of choice for their interviews, but instead the interviews had to be done over the phone or via video. This alone, created a lack of context that I feel would have improved the study's reliability. In the future, I think this exact study, continuing to use exploratory qualitative methods, could be redone with more participants. More participants would have helped to enhance the validity and increase the relevance of the findings, but also provide further data to support emergent themes.

My discussion of how my findings can be translated into a broader context opens the conversation around creating or exploring models of Indigenous resiliency in health care settings, particularly for expecting or new mothers. Future research that may inform public health promotion and health behaviors utilizing Indigenous resiliency will add to the lack of research regarding Indigenous communities' ways supporting their health and well-being, versus continuing to report health deficits.

Additionally, Brayboy (2005) informed the discussion of the use of Navajo mothers' stories as theory to inform health interventions and policy. Future analysis of the frequency and use of qualitative methods to inform policy and legislation for maternal-child health could help change the way quantitative versus qualitative data are viewed as useful or not and promote the usefulness of narratives and lived experiences as data to inform necessary systemic changes. Furthermore, Bowleg (2017) argues that qualitative methodology in general is more apt to assist in the production of new knowledge and ideas, as it utilizes in-depth and unique voices that can help structure how researchers view health inequities in a social-systemic context. Along those same lines, I would highly advise that any future research conducted with Navajo mothers in the context of maternal-child health disparities be done using a community-based participatory research approach that utilizes the patient themselves, their community, and subsequent stakeholders in the phenomenon. This approach is collaborative in nature, and often studies using this approach produce findings that more sustainably impact social and long-lasting change (Collins et al., 2018). When obtaining IRB approval from the Navajo Nation for this study, I was required to attend agency meetings where I presented my proposed research and sought public input and questions before moving forward. When working with tribal communities, I think it is important that future research is done in this similar way, where researchers also must go into the community and seek what is truly needed and valued by that community, before moving forward with their own assumptions.

REFERENCES

Akindola, R. B. (2009). Towards a definition of poverty: poor people's perspectives and implications for poverty reduction. *Journal of Developing Societies*, *25*(2), 121-150.

Allison, P., & Pomeroy, E. (2000). How shall we "know?" Epistemological concerns in research in experiential education. *Journal of Experiential Education*, *23*(2), 91-98.

Als, H., Duffy, F. H., & McAnulty, G. B. (1996). Effectiveness of individualized neurodevelopmental care in the newborn intensive care unit (NICU). *Acta Paediatrica*, *85*, 21-30.

Als, H., & Gilkerson, L. (1997, June). The role of relationship-based developmentally supportive newborn intensive care in strengthening outcome of preterm infants. In *Seminars in perinatology* (Vol. 21, No. 3, pp. 178-189). WB Saunders.

Als, H., Lawhon, G., Duffy, F. H., McAnulty, G. B., Gibes-Grossman, R., & Blickman, J. G. (1994). Individualized developmental care for the very low-birth-weight preterm infant: medical and neurofunctional effects. *Jama*, *272*(11), 853-858.

Altimier, L. (2015). Compassionate family care framework: a new collaborative compassionate care model for NICU families and caregivers. *Newborn and Infant Nursing Reviews*, *15*(1), 33-41.

Anderson, C., & Cacola, P. (2017). Implications of preterm birth for maternal mental health and infant development. *MCN: The American Journal of Maternal/Child Nursing*, *42*(2), 108-114.

Begay, R. C. (2004). Changes in childbirth knowledge. *American Indian Quarterly*, 550-565.

Birch, J., Ruttan, L., Muth, T., & Baydala, L. (2009). Culturally competent care for Indigenous women: a case for culturally competent care for Indigenous women giving birth in hospital settings. *International Journal of Indigenous Health*, *4*(2), 24-34.

Bowleg, L. (2017). Towards a critical health equity research stance: Why epistemology and methodology matter more than qualitative methods. *Health Education & Behavior*, *44*(5), 677-684.

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and health*, *21*(1), 87-108.

Brooks, J. L., Holdtich-Davis, D., Docherty, S. L., & Theodorou, C. S. (2016). Birthing and parenting a premature infant in a cultural context. *Qualitative health research*, *26*(3), 387-398.

Brown, B. (2006). Shame resilience theory: A grounded theory study on women and shame. *Families in Society*, *87*(1), 43-52.

Burns, E. (2015). The blessingway ceremony: ritual, nostalgic imagination and feminist spirituality. *Journal of religion and health*, *54*(2), 783-797.

Cashman, S. B., Adeky, S., Allen III, A. J., Corburn, J., Israel, B. A., Montaño, J., ... & Eng, E. (2008). The power and the promise: working with communities to analyze data, interpret findings, and get to outcomes. *American journal of public health*, *98*(8), 1407-1417.

Chigbu, U. E. (2013). Rurality as a choice: Towards ruralising rural areas in sub-Saharan African countries. *Development Southern Africa*, *30*(6), 812-825.

Chino, M., & DeBruyn, L. (2006). Building true capacity: Indigenous models for Indigenous communities. *American journal of public health*, *96*(4), 596-599.

Claydon, J. E., Mitton, C., Sankaran, K., & Lee, S. K. (2007). Ethnic differences in risk factors for neonatal mortality and morbidity in the neonatal intensive care unit. *Journal of Perinatology*, *27*(7), 448.

Collins, S.Collins, S. E., Clifasefi, S. L., Stanton, J., Straits, K. J., Gil-Kashiwabara, E., Rodriguez Espinosa, P., ... & Wallerstein, N. (2018). Community-based participatory research (CBPR): Towards equitable involvement of community in psychology research. American Psychologist, 73(7), 884.

Cromartie, J., Parker, T. (2019). Economic research service: what is rural. Retrieved from: https://www.ers.usda.gov/topics/rural-economy-population/rural-classifications/what-is-rural/

Delgado, R., & Stefancic, J. (2017). *Critical race theory: An introduction* (Vol. 20). NyU press.

Denzin, N., & Lincoln, Y. (2013) *The landscape of qualitative research.* Los Angeles: Sage.Devetclaw, P. (2017). Data shows huge reduction in diné speakers. Retrieved from: https://navajotimes.com/data-shows-huge-reduction-in-dine-speakers/

Dictionary, O. E. (1989). Oxford english dictionary. *Simpson, JA & Weiner, ESC*.

Enke, C., y Hausmann, A. O., Miedaner, F., Roth, B., & Woopen, C. (2017). Communicating with parents in neonatal intensive care units: the impact on parental stress. *Patient education and counseling*, *100*(4), 710-719.

Green, N. S., Damus, K., Simpson, J. L., Iams, J., Reece, E. A., Hobel, C. J., ... & March Of Dimes Scientific Advisory Committee On Prematurity. (2005). Research agenda for preterm birth: recommendations from the March of Dimes. *American journal of obstetrics and gynecology*, *193*(3), 626-635.

Garfield, C. F., Lee, Y., & Kim, H. N. (2014). Paternal and Maternal Concerns for their very low-birth-weight infants transitioning from the NICU to home. *The Journal of perinatal & neonatal nursing*, *28*(4), 305-312.

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The qualitative report*, *8*(4), 597-606.

Gonya, J., & Nelin, L. D. (2013). Factors associated with maternal visitation and participation in skin-to-skin care in an all referral level III c NICU. *Acta Paediatrica*, *102*(2), e53-e56.

Goodkind, J. R., Hess, J. M., Gorman, B., & Parker, D. P. (2012). "We're Still in a Struggle" Diné Resilience, Survival, Historical Trauma, and Healing. *Qualitative health research*, *22*(8), 1019-1036.

Goodman, A., Fleming, K., Markwick, N., Morrison, T., Lagimodiere, L., Kerr, T., & Society, W. A. H. R. (2017). "They treated me like crap and I know it was because I was Native": The healthcare experiences of Aboriginal peoples living in Vancouver's inner city. *Social Science & Medicine*, *178*, 87-94.

Gough, B., & Madill, A. (2012). Subjectivity in psychological science: From problem to prospect. *Psychological methods*, *17*(3), 374.

Gurung, R. A. (2013). *Health psychology: A cultural approach*. Cengage Learning.

Harrison, T. M. (2010). Family-centered pediatric nursing care: state of the science. *Journal of pediatric nursing*, *25*(5), 335-343.

Hardeen, G. (1994). Hogans in Hospitals: Navajo Patients Want the Best of Both Worlds. *Tribal College*, *5*(3), 20.

Hartle-Schutte, M. (1988). Contemporary usage of the Blessingway ceremony for Navajo births.Hepworth, J. (2004). Public health psychology: A conceptual and practical framework. *Journal of Health Psychology*, *9*(1), 41-54.

Johnson, A. N. (2008). Promoting maternal confidence in the NICU. *Journal of Pediatric Health Care*, *22*(4), 254-257.

Khetani, M. A., Richardson, Z., & McManus, B. M. (2017). Social disparities in early intervention service use and provider-reported outcomes. *Journal of developmental and behavioral pediatrics: JDBP*, *38*(7), 501.

Klawetter, S., & Frankel, K. (2018). Infant mental health: A lens for maternal and child mental health disparities. *Journal of Human Behavior in the Social Environment*, *28*(5), 557-569.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American journal of occupational therapy*, *45*(3), 214-222.

Krieger, N. (2012). Methods for the scientific study of discrimination and health: an ecosocial approach. *American journal of public health*, *102*(5), 936-944.

Lilo, E. A., Shaw, R. J., Corcoran, J., Storfer-Isser, A., & Horwitz, S. M. (2016). Does she think she's supported? Maternal perceptions of their experiences in the neonatal intensive care unit. *Patient Experience Journal*, *3*(1), 15-24.

Lincoln, Y. S, & Guba, E. A. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Lotterman, J. H., Lorenz, J. M., & Bonanno, G. A. (2019). You Can't Take Your Baby Home Yet: a longitudinal study of psychological symptoms in mothers of infants hospitalized in the NICU. *Journal of clinical psychology in medical settings*, *26*(1), 116-122.

Lumbee FAQ's. (2019). Retrieved March 4, 2019, from https://www.lumbeetribe.com/faqs-history

Maceika, A. The Hearts of its Women: Native American Women and the Struggle to Organize against Sterilization in the 1970s. *Recounting the Past,* 56-76

March of Dimes Foundation. (2015). *March of dimes peristats: born too small too soon in arizona.* [Brochure]. New York: Center for Disease Control.

March of Dimes Foundation (2015) The newborn intensive care unit (NICU). Retrieved from: https://www.marchofdimes.org/complications/the-nicu.aspx

Marcotte, M. (2017). *Examining the climate for Indigenous mothers in neonatal intensive care units (NICUs): an exploratory qualitative study about views of health care professionals* (Doctoral dissertation, UNIVERSITY OF NORTHERN BRITISH COLUMBIA).

Maxwell, D., Robinson, S. R., & Rogers, K. (2018). “I keep it to myself”: A qualitative meta-interpretive synthesis of experiences of postpartum depression among marginalised women. *Health & social care in the community*.

McGowan, E. C., & Vohr, B. R. (2019). Neurodevelopmental follow-up of preterm infants: what is new?. *Pediatric Clinics*, *66*(2), 509-523.

Melnyk, B. M., Alpert-Gillis, L., Feinstein, N. F., Fairbanks, E., Schultz-Czarniak, J., Hust, D., ... & Bender, N. (2001). Improving cognitive development of low-birth-weight premature infants with the COPE program: A pilot study of the benefit of early NICU intervention with mothers. *Research in nursing & health*, *24*(5), 373-389.

Milligan, B. C. (1984). Nursing care and beliefs of expectant Navajo women (part 1). *American Indian Quarterly*, 83-101.

Miquel-Verges, F., Donohue, P. K., & Boss, R. D. (2011). Discharge of infants from NICU to Latino families with limited English proficiency. *Journal of immigrant and minority health*, *13*(2), 309-314.

Muhammad, M., Wallerstein, N., Sussman, A. L., Avila, M., Belone, L., & Duran, B. (2015). Reflections on researcher identity and power: The impact of positionality on community based participatory research (CBPR) processes and outcomes. *Critical Sociology*, *41*(7-8), 1045-1063.

Morales, L. S., Staiger, D., Horbar, J. D., Carpenter, J., Kenny, M., Geppert, J., & Rogowski, J. (2005). Mortality among very low-birthweight infants in hospitals serving minority populations. *American journal of public health*, *95*(12), 2206-2212.

Navajo Native American Research Centers for Heath (NARCH) Partnership between Diné College and Northern Arizona University, Navajo Nation Department of Health, and Arizona Department of Health. 2020 Navajo Nation Maternal and Child Health Needs Assessment. 2020.

Navajo Tourism Department. (2019). Navajo History. Retrieved from: https://www.discovernavajo.com/navajo-culture-and-history.aspx

New Mexico Pregnancy Risk Assessment Monitoring System Data (2011). Report on new mexico navajo mothers and their infants, 2005-2011. Navajo Prams Workgroup.

Northern Arizona Healthcare (2019). About us. Retrieved from: https://www.nahealth.com/about-us

Northern Arizona University (2021). Leading a nation with passion and purpose. Retrieved from: https://nau.edu/aspirations/navajo-nation-president-takes-action/

Norris, T., Vines, P. L., & Hoeffel, E. M. (2012). *The American Indian and Alaska Native Population: 2010* (pp. 1-32). Washington, DC: US Department of Commerce, Economics and Statistics Administration, US Census Bureau.

Nove, A., Friberg, I. K., de Bernis, L., McConville, F., Moran, A. C., Najjemba, M., ... & Homer, C. S. (2021). Potential impact of midwives in preventing and reducing maternal and neonatal mortality and stillbirths: a Lives Saved Tool modelling study. *The Lancet Global Health*, *9*(1), e24-e32.

Onwuegbuzie, A. J., & Leech, N. L. (2006). Linking research questions to mixed methods data analysis procedures 1. *The qualitative report*, *11*(3), 474-498.

Parker, L. (2011). Mothers' experience of receiving counselling/psychotherapy on a neonatal intensive care unit (NICU). *Journal of Neonatal Nursing*, *17*(5), 182-189.

Peacemaking, I. D. (2017). DiNé SovereigN aCtioN. *Navajo Sovereignty: Understandings and Visions of the Diné People*, 160.

Reid, T., Bramwell, R., Booth, N., & Weindling, M. (2007). Perceptions of parent–staff communication in Neonatal Intensive Care: The development of a rating scale. *Journal of Neonatal Nursing*, *13*(1), 24-35.

Roberts, H. J., Harris, R. M., Krehbiel, C., Banks, B., Jackson, B., & Needelman, H. (2016). Examining disparities in the long term follow-up of Neonatal Intensive Care Unit graduates in Nebraska, USA. *Journal of Neonatal Nursing*, *22*(5), 250-256.

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative research in psychology*, *11*(1), 25-41.

Running Strong. (2018). American Indian life: the poverty cycle. Retrieved from: https://indianyouth.org/american-indian-life/poverty-cycle

Saldana, J. (2015). *The Coding Manual for Qualitative Researchers (3rd edition)*. Sage. Sequist, T. D., Cullen, T., Bernard, K., Shaykevich, S., Orav, E. J., & Ayanian, J. Z. (2011).

Theobald, B. (2020). Bringing Back Woman Knowledge: The Women's Dance Health Program and Native Midwifery in the Twin Cities. *Journal of Women's History*, *32*(4), 63-87.

Sequist, T. D., Cullen, T., Bernard, K., Shaykevich, S., Orav, E. J., & Ayanian, J. Z. (2011). Trends in quality of care and barriers to improvement in the Indian Health Service. *Journal of general internal medicine*, *26*(5), 480-486.

Shaw, R. J., Bernard, R. S., Storfer-Isser, A., Rhine, W., & Horwitz, S. M. (2013). Parental coping in the neonatal intensive care unit. *Journal of clinical psychology in medical settings*, *20*(2), 135-142.

Sigurdson, K., Morton, C., Mitchell, B., & Profit, J. (2018). Disparities in NICU quality of care: a qualitative study of family and clinician accounts. *Journal of Perinatology*, *38*(5), 600.

Sizun, J., & Westrup, B. (2004). Early developmental care for preterm neonates: a call for more research. *Archives of Disease in Childhood-Fetal and Neonatal Edition*, *89*(5), F384-F388.

Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. *Qualitative health psychology: Theories and methods*, 218-240.

Smorti, M., Ponti, L., Ghinassi, S., & Rapisardi, G. (2020). The mother-child attachment bond before and after birth: The role of maternal perception of traumatic childbirth. *Early human development*, *142*, 104956.

Sparks, P. J. (2009). Do biological, sociodemographic, and behavioral characteristics explain racial/ethnic disparities in preterm births? *Social science & medicine*, *68*(9), 1667-1675.

Stern, M. J., & Adams, A. E. (2010). Do rural residents really use the internet to build social capital? An empirical investigation. *American Behavioral Scientist*, *53*(9), 1389-1422.

Thorsen, M. L., Harris, S., McGarvey, R., Palacios, J., & Thorsen, A. (2021). Evaluating disparities in access to obstetric services for American Indian women across Montana. *The Journal of Rural Health*.

Ungar, M. (2012). Researching and theorizing resilience across cultures and contexts. *Preventive Medicine: An International Journal Devoted to Practice and Theory*.

St. John, M. S. (2019). Reconceiving the field: Infant mental health, intersectionality, and reproductive justice. *Infant mental health journal*, *40*(5), 608-623.

Vazquez, V., & Cong, X. (2014). Parenting the NICU infant: A meta-ethnographic synthesis. *International Journal of Nursing Sciences*, *1*(3), 281-290.

Visit Arizona. (2019). Arizona’s northern region. Retrieved from: https://www.visitarizona.com/cities/northern

Wallendorf, M., & Belk, R. W. (1989). Assessing trustworthiness in naturalistic consumer research. Association for Consumer Research, 69-84. http://www.acrwebsite.org/volumes/display.asp?id=12177

Weber, L., & Parra-Medina, D. (2003). Intersectionality and women’s health: Charting a path to eliminating health disparities. In *Gender perspectives on health and medicine* (pp. 181-230). Emerald Group Publishing Limited.

Wei, G., Powell, F. D., Freeman, V. K., & Holmes, L. D. (2011). Perinatal depression in minority and underserved rural women. *Perinatal Depression*, 139.

Wiebe, A., & Young, B. (2011). Parent perspectives from a neonatal intensive care unit: a missing piece of the culturally congruent care puzzle. *Journal of Transcultural Nursing*, *22*(1), 77-82.

World Bank. (2019). Understanding poverty: poverty. Retrieved from: https://www.worldbank.org/en/topic/poverty/overview

Appendix A: Demographics Sheet

1. What is your age? _________
2. What is the highest degree or level of school you have completed?
    a. No schooling completed.
    b. Nursery school to 8th grade
    c. Some high school, no diploma
    d. High school graduate, diploma or the equivalent (for example: GED)
    e. Some college credit, no degree
    f. Trade/technical/vocational training
    g. Associate degree
    h. Bachelor's degree
    i. Master's degree
    j. Professional degree
    k. Doctorate degree
3. What is your marital status?
    a. Single, never married
    b. Married or domestic partnership
    c. Common Law
    d. Widowed
    e. Divorced
    f. Separated
4. What is your current employment status?
    a. Employed for wages

    b. Self-employed
    c. Out of work
    d. Looking for work
    e. A homemaker
    f. Student
    g. Military
    h. Retired
    i. Unable to work

5. What is your current household income?
    a. Greater than $60,000
    b. $40,000-$60,000
    c. $20,000-$40,000
    d. Less than $20,000
6. How far do you live from a major city?
    a. Less than 50 miles
    b. 50 to 100 miles
    c. 100 to 150 miles
    d. 200 to 250 miles
    e. More than 200 miles
7. Do you have other children?
    a. Yes
    b. No

Appendix B: Semi-structured Interviews and Interview Scripts

Project Introduction Script:

Yá'át'ééh, I hope you are doing well today. My name is Chelsey Tarazi (or staff name) and I am doctoral student (NICU staff member) from Northern Arizona University (Flagstaff Medical Center). Thank you for letting us speak with you today. We are currently conducting a project where we want to better understand Navajo mothers' experiences in the NICU with their infants. We understand you have a child you visiting (or caring for) here today, (or you have a child who was once in the FMC NICU) and we were hoping to tell you more about our study. If you choose to participate, you will be asked to tell your story about your experiences with giving birth to a premature infant, as well as your experiences here in the NICU. For participating, you will receive a $100 gift card to Wal-Mart, which will be given immediately after the interviews are over. Your interview will be done over the phone or over video, however you prefer. Your participation is impactful, and it will help us and NICU staff better understand how to care for Navajo mothers in the hospital when they have babies who are born premature. Is this something you would be interested in? Ahéhee', we appreciate your time.

Informed Consent Script:

Ahéhee'. Thank you for your interest our project with Navajo mothers. Before we can begin working with you to tell your story, we must get your informed consent to participate. The Navajo research board, Northern Arizona Healthcare, and Northern Arizona University put safeguards in place to ensure your confidentiality and protection from any harm during this process. To ensure you understand your rights as a participant, as well as any risks, we will give you an informed consent document. This document lists what the project entails, what you should expect, what is expected from you, your confidentiality, and any risks associated with the project. Once you have read through the document, or had it read to you, you will sign the document. The document will then be stored safely in my office, in accordance with the Navajo research board's policies. Although I will state this in the informed consent document, it is important to know that you can remove yourself from this project at any time. Once you sign this informed consent, this does not mean you have to stay in the project if you do not want you. You are also welcome to ask me any questions at any time throughout your participation in this project. Since we are conducting interviews over the phone or video, I can email you the informed consent or I can mail it to you. We can only do the interview once I receive it. Do you have any questions? We will now read through the informed consent.

Semi-structured Interview Script:

Yá'át'ééh, thank you for meeting with me today. The only thing we must do today is let you tell your story and I will listen and record it. To help tell your story, I have semi-structured list of questions and follow-up questions, to help guide us through the process. I will simply ask you a question and you will tell that part of your story. I may ask some follow up questions to gather more information or to seek clarification. This interview should take one to two hours. It may take less time than that, or more time, but I want to give you as much time as you need to share your experiences. After we are done, I will ask you if you have any further questions or information, and then I will provide you with your gift card for participating. Do you have any questions? Wonderful. Before we get started, I'd like to tell you a little about myself. I am Chelsey Tarazi and I am from Arkansas, where I grew up. I've moved around a lot in my life, but now I am residing in Flagstaff, Arizona, where I am finishing my PhD in psychology. I have close group of family and friends who support me in my work. I am currently doing my dissertation project, which is why I am here talking with you today. Your participation is greatly appreciated, and I am thankful and grateful to hear your story today…I will begin recording now unless you have any further questions.

Semi-structured Interview Questions:

1. Tell me a little about yourself?
    a. Probing questions:
        i. Where are you from?
        ii. What do you do/like to do?
2. Tell me your story about your most recent pregnancy.
    a. Probing questions:
        i. What were you feeling?
        ii. What were you thinking?
        iii. What were some of the things you had to do (i.e. prenatal care, checkups, etc.)?
3. Tell me the story of your birth experience.
    a. Probing questions:
        i. What were you feeling?
        ii. What were you thinking?
4. Tell me about your experiences in the FMC Special Care Nursery?
    a. Probing questions:
        i. Anything difficult?
        ii. Anything memorable?
5. Tell me about your experiences with FMC SCN staff?
6. Tell me about your experiences with visiting and caring for your baby in the NICU?

   a. Probing questions:
      i. How did you get there?
      ii. Were there financial burdens?
      iii. What was difficult?
      iv. What was memorable?

7. Tell me some good things you hope or wish for you baby in the future?

Ahéhee'. Do you have questions or further information to share before I end the recording?

Appendix C: Informed Consent

Consent to Participate in Research

Study Title: Exploring the Experiences of Navajo Mothers who Give Birth to a Premature Infant in a Rural Neonatal Intensive Care Unit

Principal Investigator: Chelsey Lynn Tarazi, B.S.

You are being asked to participate in a research study. Your participation in this research study is voluntary and you do not have to participate. This document contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to ask questions before making your decision whether to participate.

Purpose: The purpose of this study is to explore your experience as a Navajo mother when birthing a premature infant. The goal of this study is to inform future culturally-competent care by Neonatal Intensive Care Unit staff when working with Navajo mothers and families.

Expected Duration: The expected duration of this study is one year, however, your participation will only be 1-2 hours of your time to participate in an interview with the principal investigator and any of her research team. The interview can be done in one sitting or more than one sitting depending on your schedule and availability.

Requirements and Rights of Study Participation: To participate in this study, you must identify as a Navajo woman, be 18 years of age or older, English-speaking, and had a premature infant who is or was residing in the Flagstaff Medical Center Special Care Nursery and who is expected to graduate from the NICU. You may also participate if you visited the Special Care Nursery up to one year ago. If you consent to participate in this interview, you will share your experiences giving birth to and caring for a premature infant. You have the right to remove yourself from this study at any time. You have the right to end your interview at any time. Participation is voluntary and shall not interfere with services available to the rest of the population.

Benefits of Participation: By participating in this project, mothers provide valuable information regarding Navajo mothers' experiences when caring for their premature infants. By sharing their stories, Navajo mothers may be better supported in the future when giving birth to and caring for premature infants in the hospital and NICU setting. The information from this project will be used to support culturally competent care for medical institutions serving Navajo mothers. Mothers will also receive a $100 Wal-Mart gift card for their time and participation.

Summary of the Risks of the Study: There may be emotional risks associated with re-living painful feelings as mothers tell their stories. Mothers may experience negative emotions from discussing memories of pregnancy and/or birth of their premature infant. There may be a possible breach of confidentiality, however the PI is ensuring all data collected is deidentified by using identification numbers only and no names. Another risk to this study is use of your personal time.

Confidentiality and Participant Protection: Your name will not be used in any report. Identifiable research data will be encrypted, and password protected. The information that you give in the study will be anonymous. Your name will not be collected or linked to your responses. Your responses will be assigned a number. The list connecting your name to this number will be kept in an encrypted and password protected file. Only the research team will have access to the file. When the study is completed and the data has been analyzed, the list will be destroyed so that your name will no longer be in the research records.

With your permission, the principal investigator would like to record the conversation or video conversation so they can make an accurate written record of it later. Your actual video will not be recorded, just the audio portion. Your face will not be seen by anyone other than the principal investigator. Once they have made the written record, they will erase the recordings. Your name will not be in the written record or my notes. The information that you provide in the study will be handled confidentially. However, there may be circumstances where this information must be released or shared as required by law. The Navajo Nation Human Research Review Board may review the research records for monitoring purposes.

For questions, concerns, or complaints about the study you may contact **Chelsey Tarazi.**

Chelsey Tarazi
602-510-6141
Ct667@nau.edu

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact The Navajo Research Office and Beverly Becenti-Pigman at Navajo Department of Health, P. O. Box 1390, Window Rock, AZ 86515. Telephone number is (928) 871-6929. Fax number is (928) 871-6255. You may also contact the Human Subjects Research Protection Program at 928-523-9551 or online at http://nau.edu/Research/Compliance/Human-Research/Welcome/. You may also contact the Northern Arizona Healthcare Institutional Review Board Administrator, Paula McAllister at 928-214-3616, or by email at Paula.McAllister@nahealth.com

AGREEMENT TO PARTICIPATE

I have read (or someone has read to me) this form, and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I affirm that I am at least 18 years of age and voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

______________________________	____	______________
Printed name of subject	**Signature of subject**	**Date**

AGREEMENT TO BE AUDIORECORDED (Your video will not be recorded and saved, just the audio portion)

Subject Signature:______________________________________ Date:_______________

Appendix D: Diana's Interview

PI: Principal Investigator

M1: Diana

PI: So, tell me a little about yourself.
PI: Where are you from?
PI: What do you like to do?
M1: Um, I'm originally from Pinon on the Navajo reservation.
PI: Uh huh
M1: I am 26 years old, I have three kids, and I'm working as a home care provider
M1: And I was planning on going back to school next semester for Spring 2020
PI: Uh huh
M1: To get my certificate and AA degree in um administrative services.
PI: Oh, that's great
M1: Yeah, and I like to bake, cook, and clean, and just like small activities with my kids when I can.
PI: Yeah, how old are your kids?
M1: My oldest she is 7, the middle is 4, and the youngest is 5 ½ weeks.
PI: That's right, oh my goodness. I bet you are so happy to be home.
M1: Yes (laughs)
PI: And they are all such fun ages, I love that age.
M1: (laughs)
PI: So, tell me your story about your most recent pregnancy, so with your 5-week-old.
PI: Kinda tell me, like, how did this pregnancy go?
M1: Umm, it was, um good.
M1: Umm, I didn't have, well, I don't know if I'd say it was good (laughs)
PI: (laughs)
M1: Umm I did have morning sickness throughout the whole pregnancy.
PI: Yeah
M1: But umm, it made me feel sick most of the time and umm with my first pregnancy I had mild preeclampsia so umm that was kind of scary, but with this third pregnancy, I didn't have it, um, I was taking medication for it and towards the end of my pregnancy, umm, it was umm, quite hard for me to move around. Like, I had really bad pain around my pelvic area. And, umm, other than that it was OK. It was just the pain around my pelvis that made it really uncomfortable.
PI: Right, gosh that sounds so uncomfortable.
M1: Yeah
PI: I heard you say you were scared. Were there other things that you were feeling or thinking during this pregnancy?
M1: Umm, yeah, umm, I had been, umm, a lot was going through my mind. Like personal problems and, umm, just umm, for some reason it was in the back of my mind that I did have the feeling that I was going to have her kind of early.
PI: Yeah
M1: So, I was trying to not think about in that way and just, umm, try to keep myself positive.
PI: Right.

PI: Yeah, I'm sure you were feeling a little uncertain.
M1: Yeah
PI: What were some of the things that you had to do, you know, like prenatal care or check-ups.
M1: Umm, I was getting regular prenatal care.
M1: I would go in, umm, every, I don't remember how many weeks apart my appointments were.
PI: oh, that's ok
M1: It wasn't until about 2 weeks before I had it had rained, and I went outside and I ended up slipping in the mud.
PI: oh gosh
M1: So, I had to go in to get checked and when I went in to get checked they had put me on the monitor to keep track of her heart rate and to just make sure that she was ok (upturn in voice, sounded hard to talk about)
PI: yeah
M1: and they said everything looked good, so they just told me to come back in another two weeks for another check up.
PI: yeah
M1: …and when I went back in, umm, they had put me on the monitor again, and, umm, that's when they told me I was dilated 4 cm (upturn in voice, sounds hard to talk about)
PI: mm
M1: Yeah, but, mm, I was getting regular prenatal care. Umm even, I think, umm, even with the whole, umm, the whole COVID situation.
PI: Yeah
M1: The midwives would still call me to see how I was doing and because with them not allowing patients into the hospital for a little while
PI: Oh, that's right
M1: Yeah so they would even call me just to see how I was doing, and, umm, to see how baby was doing. To see if she was moving enough and if I was having any problems. (some surprise in her voice regarding care)
PI: That is so nice of them that you were able to still get some of that check in from them during that time
M1: Yeah, it was, umm, it was different than with my first two pregnancies. It was a lot different, not having to go to the hospital for check ups (sounded impacted by this experience, like it was harder)
PI: Yeah you're, you're saying it was different
PI: did that cause any other feelings to come up knowing that wasn't a similar experience?
PI: Something that felt typical or comfortable for you?
M1: Umm, I was scared, umm, because umm, I would think like, umm, when it is time to have her, like I'm scared to be in the hospital. (very long pause after first "um", and a lot of pauses when talking about feelings)
PI: Yeah
M1: …because umm, even though the hospital is probably like the, uh, one of the the safest places, but I just kept thinking umm she's gonna be a new born and with the whole virus I was scared to, uh, umm, that's just what kept going through my mind. That was, that was why I was scared. (many long pauses, voice sounded sad)
PI: Yeah
MI: …but then I didn't have any other, umm, any other feelings.

PI: Yeah, no that would be scary. I wasn't pregnant and I was also afraid to go to the hospital, so I couldn't imagine being pregnant with a little baby and also being worried about the hospital, like, I couldn't imagine.
M1: Yeah
PI: Yeah
PI: So before I move on to my next question, anything else you wanted to share about your pregnancy or any other thoughts you wanted to share about it?
M1: Umm, no. (long pause after umm)
PI: Ok, so, tell me the story about your birth experience.
M1: Umm, it was scary. (downturn on voice)
PI: Yeah
M1: Umm, the day that I went in for check up, umm, they told me I was dilated 4 cm.
M1: So, umm, they told me that I was going to be admitted, and umm, I go to the Chinle IHS for my check ups.
PI: uh huh
M1: So there the midwife told me that umm because I was only 34, 34 ½ weeks, umm, they were umm gonna get me, umm, transported to a different hospital, because the, umm, my baby, she was going to be premature.
PI: mhmm
M1: So, they had called to um flagstaff, and flagstaff said they would take me in. so, I was flown out there and when I got there I was still uh 4 cm. (sounded upset after "4 cm")
PI: mm
M1: and, it was a long, a long labor for me. (downturn on voice, sounds hard to talk about)
PI: yeah
M1 um my contractions would go strong for like an hour, and then they would stop for a couple hours and then they would come again. It was just on and off, so, it was pretty long and, they even told me that they might just send me home, because of the um contractions just spacing out (sounded exasperated)
PI: yeah
M1 so, but, it wasn't until Sunday, Sunday morning, um, a midwife that was on call, she came in and said that she had talked to a high risk specialist doctor in phoenix. And she told him the situation with me, and , um, he suggested they just induce me, because I was already dilated at 4 cm, and, and no I went up to between 6 and 7 cm by Sunday. (sounded matter of fact)
PI: oh wow
M1 and he said that there was going to be a risk of infection for the baby if she just stayed in longer.
PI: mhmm
M1 so, later on that afternoon they started me on patosin to get my contractions going and from there my contractions started getting stronger and I had her at 9:11 at night. umm, so from Friday to Saturday, Saturday morning, I was getting really impatient. I tried walking around, doing squats, whatever I can to, um, keep the contractions going. (sounded exasperated)
PI: yeah
M1 but it just spacing out, and I ended up getting frustrated, but eventually I had her and um during the first hour she did good on her own. (sounded relieved)
M1 She was breathing well on her own and her oxygen started going down so they had to take her and at the same time I was taken into the OR because the midwife said I was losing too much blood and she couldn't find where I was bleeding from. (sounded tired or exasperated)
PI: yeah

M1 so, they took her down to the NICU and I was taken into the OR and I was in the OR for about an hour. And I don't remember. I just remember waking up in another room and um in my culture we're, we're not supposed to um take another organ from um somebody else, or get blood transfusions and stuff like that. (LP
PI: yeah
M1 so, but I ended up getting a blood transfusion, because the midwife told me um that I lost 50% of my blood volume.
P: mm
M1 and she said, and before um, when I was admitted to the hospital in flagstaff, they asked me like if anything were to happen, um, I would be willing to get a blood transfusion, and I said, I said no because it goes against my tradition. (upturn on voice, sounded certain)
PI: yeah
M1 but she said that um, if I wouldn't have gotten the blood transfusion that I um, that I would've bled out on the table. (DT) And, it was scary, like, just to hve that, that thought going through my head. like, I don't know, it was just, it was scary. I had never experienced anything like this with my other two pregnancies. (scared)
PI: yeah, That does sound really scary.
M1 Yeah, it was.
M1 my husband was pretty shaken up about it too, um, like when they had to rush me into the ER, the OR. (up
PI: yeah
M1 Yeah, and, he said he just kept thinking, thinking about, um, he just, it was just running through his mind too while he was waiting for me to come back out. (sounded sad)
PI: yeah
PI: how do you
M1 yeah (sounded sad)
PI: what were you thinking and feeling, you know, I know you said you told them no for a blood transfusion and then they gave you one.
PI: how did that feel after the fact?
M1 um, I, um, I was just glad that they did it because like (very long pauses after I and um)
PI: yeah
M1 if they didn't then I wouldn't be here. (long breath after "wouldn't", sounded sad)
Pi: yeah:
M1 and, I was just glad that they, they ended up, um, giving it to me. (upturn, sounded relieved)
PI: yeah
M1 even to this day, it's still, um, it still scares me, like, I couldn't, I can't imagine my kids not, not having me there? (sounded scared, sad, upturn after "there")
PI: yeah
M1 so, it puts a lump in my throat sometimes when I think about it. (breathing out after last word)
PI: yeah I'm sure. I know birth experiences are such a personal and intimate thing, so I really appreciate you sharing that with me. it sounded like a really scary process for you, it really did.
M1 yeah (sounded exasperated)
PI: so, anything else you wanna share with me about that before we move to the next question?
M1 umm, mm, no (long pause)
PI: ok, so tell me about your experiences at the special care nursery where your baby stayed
M1 it was good, um, the nurses and doctors, they were really nice. Um, I loved how they, um, cared for the little ones in the nursery and how they, um, they tried to make the parents feel as

comfortable there and having them try to take care of their kids even while in the nursery. like, they ask um, they ask, um, if you want to give your child bath, and then they have you change their diapers. Even the um, the o2, oxygen probes they have on, they have you change that and um and just like they try to have you involved in your child's care while in the nursery. (breaths during this, upturn)
PI: Yeah
M1 it was weird, I, um, even though I was I just wanted to go home, they made you, they made you feel, um, that sense of care that, that you're, um, that you feel like you're missing. (sounded tired after "home")
PI: yeah
M1 yeah, so it was good and the nurses were really nice, and um, they would um, constantly ask if we needed anything and mm yeah. it was good.
PI: was there anything that was particularly difficult about your experience in the special care nursery?
M1 um, yeah, um, considering that I have two other kids, it was hard trying to, at the beginning, that first week, um, I had a lot of guilt. Like, when, when I wasn't there, um, with my baby, I felt like, I needed to be there with her all the time and it just made me cry and my other two kids were out there with us for a week, for a couple days, and I would try to spend time with them as well, but at the same time I still had that guilt feeling that I needed to be at the hospital with their sister. I talked about how I felt with my mom, my husband, and my sister. (long pauses throughout this, sounded exasperated, lots of upturn)
PI: yeah
M1 and, they all told me the same thing, that, um, it's only temporary that my daughters gonna be there. it is good that I was spending time with my other kids because they missed me too and that not to, just be strong. so I think that was the most difficult part, was to balance that tension between my kids. My oldest is doing the whole online virtual learning (sounded sure of her decision and sounded confident)
PI: yeah
M1 so that was the other thing that was difficult about it. Talking to her and she knows how to navigate through the whole, um, website where she does her work.
PI: yeah
M1 so, I just told her to get as much done as she can and um that if she needed help she could video call me.
PI; yeah
M1 that was the most difficult part about it. (sounded matter of face, downturn in voice)
PI: yeah
PI: anything particularly memorable about your experiences in the nursery?
M1 um, I think it was just um, that alone time that I had with, with my baby there (sounded soft, loving)
PI: yeah
M1 um, I was there mostly all day with her and I would just sit there and just talk to her, talk to the nurses about how she was doing and I think it's the bond that she, she had with some of the nurses. some of the nurses really um, like grew attached to her. (long pauses, thinking, sounded soft and happy)
PI: yeah
M1 I think that was um it was, it was a good thing that, um, that people that um that take care of her for a few days out of the week to um like how they talk to her and how they care for her and it was just nice seeing that. (sounded happy, content) (downturn on voice, sounded relaxed)

PI: yeah
M1 I think that's most memorable thing for me from being in the NICU, that um that bond that some of the nurses get with the kids there.
PI: yeah, that's a good Segway. My next question, I'm curious about your experiences with the staff at the nursery and were they positive, were there some negative? overall it sounds like you really enjoyed the staff there
M1 yeah um all the staff were, they were really nice. we never had any, um, we never had a negative situation with any of them. They were all welcoming and um they would always ask if we needed anything. They would always ask, like, or they would make sure um if we didn't like something that we tell them. But, everything was good. (more upturn in voice, louder and higher pitched, long pauses) we really liked the, the nurses.
PI: that's great. Did you have anything else to share about that before I go to my next question?
M1 mmm, no
PI: so you've already touched on this a little about, you know, talking about thing you got to do with your baby. I'm just curious about more of your experiences with visiting and caring for your baby while she was in the nursery. did you have to go back and forth between home and the nursery, did you have a place to stay, what was that all like for you?
M1 um the good thing about, um, having a relative in the hospital in flagstaff, they offer a room at um a place called the Taylor house
PI: that's right
M1 yeah so, um, we stayed there, um, from the day that I was discharged to the day that um our daughter was discharged we stayed there. We didn't have to pay anything, everything was taken care of through the hospital. so it was pretty easy getting around. it was just right across the street from the hospital. When my husband had to leave back to work, I just walked over to the hospital in the morning and then at night I would get a ride back to Taylor house from the security (sounded relieved and happy)
PI: yeah
M1 so, it was good, um, that's what I liked about um about it. The hospital offers that for the family of patients in the ICU, in the nursery. (sounded content and happy)
PI: yeah, so tell me about your experiences about caring for your baby in the nursery. I know you said you got to bathe her and change her diaper, what other type of experiences did you have in caring for her with the staff there.
M1 um, um, it basically just everything that I would do here with her at home, it's just I would have to, um, feed her only at the times that um, that the schedule that they had her on. I would have to let the nurses know about her wet diapers and um the staff were really helpful when I would um try to breast feed her, like when I would try to get her to latch on. I think we held her most of the, like the entire time we were there with her we would just hold her (long pauses, laughed after "held her", sounded happy)
PI: yeah
M1 and just talk to her and yeah I think its just like um having her at home, but there we just had someone looking over us (upturn, sounded thoughtful)
PI: yeah, was there anything difficult about caring for your baby in the nursery or anything particularly memorable?
M1 umm, no nothing really difficult (sounded easy going, certain)
PI; that's good
M1 I think the only thing that's kinda hard about it is all the chords and everything from the machine that has to be hooked onto her. I think that is the only thing um, the only thing that I

didn’t really like, but she needed it. (long pauses, long drawn out words, sounded exasperated when remembering)
PI: yeah
M1 and the most memorable thing about it is that the, the one on one that we had with her um because here at home like when we give her all that attention her brother and sister get jealous (laughs, sounded happy)
PI: (laughs)
M1 so it was nice just having that alone time with her (sounded upbeat, happy, thankful, voice softer)
PI: yeah
PI: when you think about your culture and identifying as Dine, you know how did that impact your caring for your baby in the NICU and impact your experience at all, if at all.
M1 um, it, um, I think out of all the families there I think we were um, I think that about a fourth of the families there were Native American (very long pause after “it”, many long pauses throughout this)
PI; yeah
M1 I noticed two other families there. one was from Hopi and one was from here at pinon as well. In my family we’re, we’re very traditional, so whenever um, whenever there is a loved one in the hospital or somethings wrong, we always pray and have like a small ceremony. After her second week in the NICU we came home back to the reservation to have a ceremony done for her. um, it was good, um, I think um, being native American and having to go through that, it has um pros and cons that go with it (long pauses, thinking)
PI: yeah
M1 the good thing about it was like um we never stopped praying for our, our daughter, and the well I don’t think there’s really any um cons that could go with having a, with being native American and having um a baby that is in the nursery (sounded confident, sure, thoughtful)
PI: yeah, thank you for sharing that. anything else you want to share before I go to our last question
M1 um, no.
PI: so tell me some things you hope for or wish for your baby in the future.
M1 um, I hope, that she, that as she grows older, um, with born being premature, that she won’t have to have um, she won’t have to have um, constant visits to the hospital, and that she, she just grows, she grows strong, and, and that everything with her health is good, um, mm, yeah, I think that’s it. That just um she won’t need visits to the hospital that often. (long pauses, thinking a lot) (<u>very</u> long pause after “good”)
PI: thank you for sharing that. that was my last question, before I stop the recording is there anything else you wanted to share or anything that popped up in your mind as we were talking or running through your mind or any questions you had for me
M1 um, no, no questions.
PI: alright perfect.
M1 ok
PI: well, before I leave, any other thoughts and questions? I know you probably want to spend time with your baby and your kiddos
M1 um, I think just like uh a positive message to other, other mothers that um, that have to go through this similar situation is just to be strong for your little one. (long pauses, thoughtful sounding)
PI: yeah

M1 it’s only temporary and um just think about the care that your little one needs, and, don’t, don’t rush the, the process, um, your baby will, will adjust on his or her own time. (sounded confident and helpful). And that’s it (laughs)
PI: thank you for sharing that. You know your story is, you went through something that seemed to feel really scary and uncertain and then now you’re home with your baby
PI you are just as strong as you are telling other moms to be
PI: You have no idea how much I appreciate you sharing this with me today, so thank you so much.

Appendix E: Cori's Interview

PI: Principal Investigator

M2: Cori

PI: Tell me a little about yourself?
M2: Hello my name is [participant's name] and I am 28 years old. I am a Navajo woman who gave birth to my son who was 6 weeks premature back on June 15, 2020. I also have a little girl in my custody who I have been raising since she was just 6 weeks of age.
PI: Where are you from?
M2: We live in northern Arizona in a small community called [participant's hometown] on the Navajo Nation
PI: What do you do/like to do?
M2: I like to read books all the time and when I have free time I love to ride horses.
PI: What are things you like to tell people about yourself?
M2: I am really shy. But when you get to know me I am very out spoken and fun.
PI: Tell me your story about your most recent pregnancy. What were you feeling and thinking during this time?
M2: My whole first trimester I was fighting morning sickness. The 2nd trimester I was craving watermelon, pickles, and orange juice like crazy. But somewhere along the way I started to suffer from constant heartburn which made me watch what I ate. By the time my 3rd trimester began I was diagnosed with Preeclampsia which meant I had high blood pressure but was prescribed any medication for which meant I would most likely deliver early. When I found out I was pregnant it came as a surprise because about years ago I had a really bad accident where I fell off the horse and he ran over me and I got really hurt. My menstruation started to become off and my periods became spaced out to where it was like I was starting menopause. The doctors just told me that there was nothing wrong with me and to just take prenatals to raise my hormone levels. But that didn't work so I sought out tribal healing which came in the form of a traditional Hopi Chiropractor who fixed me then told me that it would be really difficult to conceve because I had twisted or stretched my utertus. So I paid no mind and thought ok then its not meant to be even though it really hurt me. So my friend and I just carried on our relationship and boom 10 years later I am pregnant.
PI: What were some of the things you had to do (i.e. prenatal care, checkups, etc.)?
M2: I had monthly OB-GYN appointments and took my prenatals every day like prescribed. My family would go on daily walks with me until I would get really sore from my walks on my lower back and my groin muscles. I followed my traditional beliefs to the T. Never did or ate anything which I wasn't suppose to.
PI: Tell me the story of your most recent birth experience.
M2: So it starts 2 days before the birth of my son. On June 11, 2020 we were returning from a family trip to Colorado when two of my younger siblings were tested positive for COVID-19 we decide to get tested the next day because it was already after 7pm when we got home. June 12 I woke up to my feet and hands really swollen with a gnarly headache and I remember my Doctor telling me that if I get a headache that doesn't go away with Tylenol I should go to the ER so that's what I did. So we went to get tested and I was tested negative but my mom was tested positive for COVID. My blood pressure was sky high and I was in danger of having a stroke so they admitted me into the maternity ward where I was hooked up to medications. So me being

34 weeks pregnant I couldn't deliver there in Tuba City so I was air lifted to Flagstaff Medical Center in a helicopter. June 13 the Doctor and Nurses concentrated on getting my blood pressure under control to get me to 35 weeks I was given different medications. June 14th the doctor came in and told me that they had no choice but to induce me so I could give birth. So I was then induced at 230pm that day but wasn't feeling any contractions that night and slept. But my mom having COVID wasn't able to be with me so we called one of my Aunts who agreed to be with me, June 15th I started to feel my contractions about 130am but they weren't that painful they just felt like menstrual cramps. My aunt arrived at 730am when the contractions started to pick up, the doctor came in at 330pm and popped my water that's when things really got going. At about 545pm I felt like pushing and the midwife came in and at 559pm just one minute shy of 6pm my son was born at just 4lbs 13oz.
PI: What were you feeling?
M2: I was afraid and heartbroken that my mom wouldn't be with me for the birth of my first born. But I was afraid that she wouldn't make it that COVID wouldn't allow her to be a Grandmother and would take her from us before meeting her Grandson.
PI: What were you thinking?
M2: I was excited to be a mother because I got plenty of practice with my siblings and I was always babysitting for my aunts and of course my daughter was the first child I took care of on my own even though it was after 6 weeks.
PI: Tell me about your experiences in the FMC Special Care Nursery? Anything difficult?
M2: Nothing difficult ever happened while my son was in the special care nursery.
PI: Anything memorable?
M2: Every mile stone that my son Caleb passed made me extremely happy and excited because it meant that he was that must closer to being discharged from the Nursery.
PI: Tell me about your experiences with FMC SCN staff?
M2: All the staff was very helpful and accommodating especially since they knew I was from about 100 miles out of town and had to rent a hotel room for the duration of Caleb's stay in the Nursery. Even opening up the family room for me to sleep there and be with my baby more. Everything I needed they helped me with. My favorite nurses were Beth and Ann they helped me feed him and do sponge baths even if it was 2nd nature to me but he was just so small. They even lent me their ears for when I needed to cry because I missed my daughter so much that I would cry my heart out til I had no more tears. We were inseparable from the day she came into my life we were always together. She spent every night in my arms that being left without a goodbye and an explanation for why I was being left behind at the hospital was hard on the both of us.
PI: Tell me about your experiences with visiting and caring for your baby in the NICU? How did you get there?
M2: I have my own car which my aunt brought for me when she came for the birth of Caleb.
PI: Were there financial burdens?
M2: Not really various family members came together and helped me with my car payments and different bills so I had the money to pay for my weekly rates in the hotels. I spent a total of 3 weeks in the hotels after I was discharged and 2 weeks of that were spent with my children with me.
PI: What was difficult?
M2: Learning how to care for a newborn baby and waking at all hours of the night.
PI: What was memorable?
M2: Watching my baby grow every day and watching my daughter become attached and protective of her new baby brother.

PI: Tell me some good things you hope or wish for you baby in the future?
M2: For the future I hope my son has a very long and healthy life. I wish that his father and his family come to except my son and build a relationship with him. If not I am fine with it and just happy that I have a healthy baby boy.

Appendix F: Renee's Interview

PI: Principal Investigator

M3: Renee

PI: My first question for you, is just to tell me a little bit about yourself. You know, where you're from, what do you like to do, what you're doing currently in your spare time.
M3: Um, well, I am, I am 29 years old, this year I'll be turning 30 (laughing)
PI: Uh huh
M3: Um, sorry can you hear me?
PI: Yeah I can hear you great.
M3: Oh ok. I'm 29 years old, I'll be turning 30 this year.
PI: oh wow, ok.
M3: Um I've lived in Arizona my whole life.
PI: OK
M3: Um just different cities I've kind of lived in. But for right now we are living here in Dilkon Arizona which is here on the Navajo Nation. Um in one of the public housing for rentals. Um I have four kids, the oldest one is 9, the second oldest is 8, and the third one, she's my only girl, so she's 3.
PI: aww
M3: Then there is *** junior, who is 15 months.
Pi: wow yeah
M3: Me and their father (laughs) are not officially married yet
PI: uh huh
M3: So we are just common law, but we've been together for about 11 years now.
PI: wow that is a long time!
M3: so, yeah, so, yeah, that is how long we've been together and we are planning on officially building our own place on our own land here on the Navajo nation in Dilkon, so we are really excited to start that.
PI: Wow that is so exciting, how far along in the process are you?
M3: um well right now um we are still figuring out the planning of the floor plan. We had one but of like, and we talked to the guy who wants to do our plumbing for us which is like a relative, um, with him, he's like you don't have to jus have one restroom inside, you guys can have two restrooms, one in the master bedroom and one on the outside, so I was like OK (laughs) so we had to draw another plan
PI: (laughs) yeah
M3: But we just kind of draw it out, we drew it out, and then I sent it to my dad, and my dad does like the floor plans for us
PI: uh huh
M3: so, yeah it's pretty exciting.
PI: Wow that is so exciting. That is awesome. When do you hope to have it done by?
M3: Um, I'm kinda hoping we get it, we try to get it done by the end of this year.
PI: yeah, yeah, wow. Well that is awesome. That will be so nice for you and your family and to have your own place and space and just like how you wanted it.
M3: yeah, we are so excited.

PI: yeah, wonderful. So I want to transition a little bit into talking about your most recent pregnancy. Tell me your story around that and kind of how it went for you.
M3: Um, well my most recent pregnancy was with junior, who was my last one.
PI: uh huh
M3: Um I think in the beginning we kind of had a hard getting um pregnant. It took us maybe about 3-4 months or 3-5 months, trying to get pregnant. We just weren't getting pregnant at that time. And then until finally, like, we just kinda stopped trying and then all of a sudden we were like, we're pregnant! (laughs) and um, we found out, and then I think a month or two a month into the pregnancy, I kinda, I bled a little after I got done using the restroom. I bled a little and I freaked out. And I was like oh my gosh why am I bleeding?
PI: yeah
M3: And then I told my husband, I was like, I told him, I am bleeding. He was like, are you ok, and I was like, I'm ok, and he goes ok well you better go get checked out and this and that, and so we scheduled an appointment for like the next day and it was just that evening it happened only once. Then after that, the rest of the pregnancy I did not bleed or anything, baby was ok. Until, um, I would say maybe 6 months when you start really showing, they said I wasn't showing yet. And they're like I wonder what's going on. By then I was still doing my monthly check-ups with the doctor and they're, I think about 6 or 7 months they started having concerns, of I think you're baby you know, it's still, he or she is still too small and um
PI: yeah
M3: And stuff like that, they were telling me. And I was like, I don't know. And I would hear from my mother in law like, "you just look like you got chubby you don't look like you're pregnant and you're like 6 or 7 months already" and I was like I don't know, maybe it's a girl, maybe it's a girl.
PI: yeah
M3: That's why I'm so small and so I was hoping for a girl (laughs)
PI: (laughs)
M3: and so I was like maybe it's a girl and that's why I'm so small, because when I was pregnant with my boys I mean I was already showing at like 5 months (laughs)
PI: yeah, yeah
M3: um, so, I don't know, so maybe it's a girl, that's why. So I was all excited and we tried doing an ultrasound, um, maybe like at 7 1/2, 8 months,
PI: uh huh
M3: we did an ultrasound to see if we can find out what the sex was gonna be, and we couldn't find out, because, um, the baby kept having its legs closed and it wouldn't show us. So we were like ok well I guess we won't find out (laughs)
PI: (laughs) yeah
M3: so we just kinda left it like that and then about 8 months came a long, I wasn't as big
PI: yeah
M3: I wasn't as big either and then my doctor was like I'll send you down to, um, I'll send you down to Phoenix area
PI: mhmm
M3: that does like a more, a more in-depth ultrasound, and you know like do your bloodwork and see what's going on and to see if anything is going on with the baby or you, or something.
PI: yeah
M3: so, we did that, we waited, we were here for like uh, after that appointment, I think we had the next appointment down in phoenix which was like a week later, and we had gone down to phoenix and I think by then I was like 35, about 30, about 35 weeks.
PI: uh huh

M3: and we had gone down to phoenix and the doctor, the doctor was like, um, they did all these ultrasounds, and we still couldn't find out the sex (laughs)
PI: yeah
M3: Even though we really tried (laughs)
PI: (laughs)
M3: um, so we were like ok well we will just leave it and you know we will meet he or she when she comes out, so we're like ok, and they did, um, and it turns out they said that um I might have had, or the baby, had, I think what's called Trisomy 13 or 16
PI: oh, ok
M3: where it's, where yeah, the baby just lives a little bit and then passes
PI: yeah
M3; so that's what they were kind of saying, like the bloodwork that had come back, and um, they had, I never had to go through this with any of my pregnancies and they had to like stick a, what do you call it, my amniotic fluid, wasn't um, wasn't enough.
PI: oh
M3: like, a little, little bit, so when they had to get some of that amniotic fluid with the needle, um it was really hard to get because I was very low on it.
Pi: yeah, yeah
M3: and they had to really kind of push down my stomach and try to get some fluid, like in a place where they can actually get some, so that was, it was painful.
PI: yeah I'm sure
M3: (laughs) and during the in-depth um like the ultrasound, was really hard on like, my stomach area, was a lot of pushing and everything, but we had to get through it for the baby, so
Pi: yeah
M3: I was willing to do any kind of test or any kind of anything, just to see what was going on, because I was like this never happened to me before, so I was like ok well we'll try that, so.
Pi: yeah
M3: when we were in the hospital, just me and my husband were there, maybe for like, let's see we were down there for a day to do the ultrasounds and stuff and they're like, I think you just, you know, need to check back into the hospital and then from there they're like, we're going to have to give you the steroid shot just because the baby's so small, the baby will have to come out a little early.
Pi: yeah
M3: so, um from there they had to send us back to the hospital and come to find out, I guess there was something going on with the umbilical cord, it wasn't functioning well enough to uh give the baby the nutrients he wanted.
PI: wow
M3: so there was like a, um, like a, I guess like a blockage or something in the umbilical cord.
PI: yeah
M3: so that's why the baby growing as much the way he should be
Pi: yeah
M3: um, so, but then we were, after I got my first shot of the steroid um for the baby's lungs, they were like we're gonna have to keep you overnight, and then you can do the next steroid tomorrow, around this time again, and then I'm hoping the doctors will let you go home. So I'm like ok, so me and my husband stayed there at the hospital for one night. Um, the next day, is when the doctor kinda, the doctor kinda gave us the information of I think your baby has trisomy 16 or 13.
PI: right, right

M3: and he explained it to us and it was, it was scary, like really scary to know that and just like unbelievable and scary and so many thing went through my head, you know, I was emotional, I was crying, and everything was, no this can't happen you know, and then
PI: yeah
M3: and my husband was like you'll be ok, we'll be ok, we'll, you know, traditionally, um, he was like, we can get a prayer.
PI: yeah
M3: like a medicine man prayer. He's like we can get a prayer done for baby for him to be ok and
PI: right
M3: and stuff like that so, he calmed me down and I was like, ok, and the doctors wanted us to stay there until I was at least 37 or 38 weeks, for the baby's lungs to be like mature enough to be strong
PI: yeah
M3: but I really fought against it and I was like well, um, and they were like, we want you to stay here to keep an eye on you. We don't want you to have um, what is that thing called where um, where the baby is gone inside you, what is that called?
PI: oh um a miscarriage?
M3: um yeah like a miscarriage? Yeah he was like we don't want that to happen to you. Oh a still birth.
PI: stillbirth, yeah
M3: we don't want that to happen to you. I was like, ok, and he goes, so if you leave it's gonna be on you and you'll be on your own, we just want you to stay here to keep an eye on you, but if anything comes up over the weekend, you know, come back Monday, and once you come back Monday we're gonna keep you in the hospital.
Pi: yeah
M3: (laughs) so I was like ok, so we got let go that Friday, we came back into Dilkon, and um, we got a little, we got a prayer done for the baby
PI: oh good
M3; and, um yeah, we got a prayer done for baby and medicine man said it was gonna be ok, it's gonna be ok, um you know just stay strong, stay strong and be there for baby.
PI: yeah
M3: so we were like, ok, and Monday comes and uh we, by then, I was like maybe 36 weeks and like 3 days or something and um we got back to the hospital Monday and then I think within a few, we stayed in the hospital for a couple more days until, I was thinking I was gonna have, cause um, this whole time he was breached.
PI: oh ok
M3: and I never like I never wanted to have a cesarean
PI: yeah
M3: like with my 3 older ones, you know I always had them naturally and like with no pain medicines or anything, so I was like he's my fourth one so I'm gonna have him natural. I had this birth plan like I'm gonna have him natural and everything, and here all this turns around and then he was still breached when they had done the ultrasounds just the day before. They were like um, they told me, once you're, we're not gonna wait till you're 38 weeks because once you're 38 weeks your baby is still probably not gonna grow as much, so once you're on day, starting the first week, starting the 37th week, the first day of it, is when we plan on inducing you and you're gonna have the baby.
PI: yeah

M3: so I was like um, it was like so shocking because I never had to like get induced or anything and I was like ok, I was like nervous and everything

PI: oh gosh

M3: I was like ok. And then they're like wait was the baby breached and I was like yeah the baby was breached the last time we checked so I'm not sure if he's breached still but I kinda feel him kicking up here still

PI: yeah

M3: or down here. The day before I had my cesarean they checked to see if he was breached still and he was so they were like well we'll schedule your casern the next, tomorrow morning, which was gonna be at like 8:30, so we didn't get in there until like 9:20 and 9:15 and I had him cesarean at like 9:45 or 10 that morning. Um, and then after having him, he, he was really small. He was born two pounds and 15 ounces.

PI: oh wow so small

M3: at 37 weeks, so he was pretty, still pretty tiny

PI: yeah

M3: but it was really good to see him once he came out they were like it's a girl and I just started crying and I was like oh my gosh it's a girl and they were wait no it's a boy just kidding it's a boy (laughs)

PI: (laughs)

M3: and I was like oh my gosh, so even when he came out they thought he was a girl so, after cleaning him and everything they were like oh it's a boy (laughs)

PI: (laughs) wow

M3: and I was like ok well since it's a boy he's my last one and just being there dad was like, I want him to be a junior so I was like, OK. (laughs)

PI: yeah

M3: so, and then after I had him, um, they had took him up to NICU, there at, I had him at __ __ hospital, he was up at NICU and for, lets see, October, November, December, then January 1st of 2020 was when he got released from NICU to go home. But the first, when we were there he was on oxygen for a little bit and then he had one of those things down his nose for feeding

PI: yeah

M3: and then he was like under one of those um those blue lights, I forgot what they were called

PI: yeah

M3: yeah, he was underneath one of those. He was in a little incubator, so tiny,

PI: yeah

M3: and I didn't get to see him until like the day after or later that night I got to finally see him so.

PI: yeah

M3: it was pretty hard, and not able to ever actually hold your baby after, right after birth and he has to go up in (ugh) the NICU and leave you and I was like oh my gosh I cant believe I just you know did that and went through all that and then

PI: yeah

M3: he was in the hospital after birth until Jan 1 of 2020 um and then it was just, he was just, they called it um severe IUGR.

PI: uh huh

M3: um so he had a severe growth restriction so um and then on top of that he had a, what do you call it, and then I guess I think they like look over everything and I guess they found, I think

within a few weeks of having him maybe a month after having him um they said in his heart one of the little arteries that should close on its own hasn't closed yet
PI: oh ok
M3: um so with that, so they were like um he has to have like a heart surgery
PI: oh
M3: so I was thinking like a heart surgery like cutting and stuff
PI: yeah
M3: so I was like oh my gosh no, no he's just a baby I can't have him go through that and they're like not it's not going to be that kind of surgery it's just you know we can go into the biggest vein all the way up there from his leg
PI: oh ok
M3: all the way in the vein all the way up towards his heart and they did um, it's called a PDA closure
PI: ok
M3: so they did that and they put like a little um coil, coil in there.
PI: oh ok
M3: so it would close. They closed it and then they said he sounded really good after that so
PI: good
M3: and with that I had to even you know sign papers and stuff and then I had to get a card saying that he just had, he did have a PDA closure and um that the coil is in there and it's in place and I have a little card that says that. (laughs)
PI: (laughs)
M3: and um, um, he went through that I think about within a month after having him and then um when he started bottle feeding when they tried him on bottle feeding um he just wasn't really taking um the bottle like he should. Like he didn't get the sucking motions down and every time he tried he would kinda like um, it would go down I guess the wrong pipe and it would go into his lungs and he would kinda get sick from it, and so they just ended up you know, um not feeding him and then I guess turns out, he had a um, so they just kind of like, wanted to do the G-tube just for him to get feeds.
PI: right
M3: and hold the feeds down so they we're gonna do that and before they do the G-tube insertion I guess they do that one dye where they put it in the baby's nose and it goes all the way down and they see, like I was in there the whole time when they were doing this dye and it goes into the baby's intestines and everything and they're like oh we see something that's going on in his intestines and then they're like it's kinda twisting. It's what you call a malrotation.
Pi: yeah
M3: and I was like oh my gosh and they're like we need to get that, we need to get that fixed, we need to do the surgery, it's called a malrotation rotation surgery. I was like oh my gosh its gonna, and he was already within what two months.
PI: oh wow yeah
M3: and I was like he can't go through that and I was like oh my gosh and I was this whole time I was down in phoenix with him just by myself, going into the hospital every day, and spending all day with him and then going back into the Ronald McDonald house at like 10 o'clock at night.
PI: yeah
M3: it was the same thing everyday you know getting there by 9 or 10 o'clock and then staying there all day just to be with him
PI: yeah

M3: it was a lot and for him to hear that he had to do the malrotation surgery and the g-tube insertion, it was scary
PI: yeah
M3: but um, they got it done and he did ok with both of them and then it was just learning how to do the g-tube piece before we got to go home
PI: right
M3: and just for him to gain weight, they wanted him to be at least, I think he had gone home when he was still, how many pounds was he, he was still really little.
PI: yeah
M3: It was about almost 5 pounds before he actually got to go home so he was still really small, but after the g-tube and the malrotation surgery it was just mostly working on his feedings and getting his weight back up and just everything you know about getting his weight up, making sure he's growing and stuff like that before we had to go home. So I had to get used to feeding him with his g-tube and just giving him a bath (laughs) just giving him a bath with, was still kind of hard because he was really so tiny.
PI: yeah
M3: (laughs) so I had to get used to doing all of that myself and I'm glad I learned in the hospital you know
PI: yeah
M3: so I had to do all of that before we got to go home but thankfully we got to go home exactly on January 1st 2020 so that was really exciting (laughs)
PI: oh good yay!
M3: so we got to go home and then I think within since January of last year um we were home for a little bit, and then something had gone, I think he had gotten sick and then that's when we ended up at the special care nursery in flagstaff
PI: oh ok
M3: so we, yeah that was when we ended up there
PI: so before we go into your experience at the one in flagstaff, I wanna ask, go back to your c-section, with the birth, and you told me a lot about that, but I'm curious what were you feeling and thinking during that time. You said didn't want a c-section and you had all these feelings and thoughts and I was curious about what those were during that time.
M3: um, well, uh, me and my sisters delivered. I have an older sister that's older than me and she never had a cesarean or anything so I never knew anything about it and my sister that's a year younger than me, she never had a cesarean so like I didn't want to have a cesarean.
PI: right
M3: at all, and but I did get in contact with one of my friends. I did tell her about my pregnancy, and when she had her first cesarean she was still in high school, like a senior. We were both seniors and um, she had a cesarean and back then I don't remember asking my friends then like how does it feel, you know, having a cesarean, did it hurt? She goes, oh it didn't hurt it just hurts a little bit after
PI: yeah
M3: but during the process it don't' hurt and I was like how does it feel and she was like she puts her arm on me and she's like you just kind feel it tightening and it feels like, you know how a cat like um I guess paws on you, like pushes down on you (laughs)
PI: yeah (laughs)
M3: she did that to my arm and exactly how she explained it was how it felt, um, you couldn't feel anything but you can just feel like the tightening
PI; yeah

M3: like just the tightening of it and then but that process it just was doing that, I was, when I had to first get the shot for my back, for like my lower body to get numb and so they were like ok you can lay down so I laid down and then it took a couple seconds a couple minutes to get it to go down, so I was like ok (laughs) hold on
PI: you're good take your time
M3: um but yeah so I was like ok then so once I had laid down on the operating bed or table um I just felt like, I just felt like my toes and everything start tingling you know how you sit on it too long it starts falling asleep like a tingle
PI: yeah
M3: I felt that tingling sensation and I just felt like I had to move my legs like I don't know its just a weird feeling because I've never had that happen (laughs)
PI: yeah, yeah
M3: and I felt like I wanted to move my legs so I could shake it off but they said whatever you do just don't move and I was like ok so I had to even work through that I was like ok now I feel my legs tingling and I can't move but it feels funny (laughs)
PI: (laughs)
M3: um it's just kinda weird and after that it just went completely numb like I couldn't feel anything and they're like ok well we're gonna try the pinching test they call it and if you cant feel anything then we're gonna start and then they're like we'll tell you what time we're gonna start cutting and stuff like that so I was like um ok.
PI: yeah, wow
M3: and I guess they did the pinching test they're like did you feel that and I was like no I didn't feel anything and they're like ok she's ready and then like a minute or two they're like ok well we're cutting so.
PI: yeah
M3: and they're trying to get baby out when I was feeling the motion tugging
PI: mm yeah
M3: yeah and then I just remember holding my husbands hand and I was like oh my gosh this feels so weird I was telling him it feels so weird, I can just feel it tugging and I was like ugh, and it feels cold in the operating room, so, having the warmth of my husbands hand just completely calmed me down
PI: aw, yeah
M3: like it completely calmed down cause like once you start getting cold and shivering, is how I felt, is cold and shivering, um, numb, but I can't feel and I'm just kinda, my mind and everything is everywhere and I'm like oh my god and so I told my husband to hold my hand and he held my hand and just the warmth of his hand like completely, completely, like just calmed me down and then it took them like maybe a few minutes and that's when we heard the baby cry and I was like oh my gosh and that's when they're like it's a boy and I'm like oh and then they're like it's a girl and I started crying and like yes the baby's here and they're like it's a boy! (laughs)
PI: (laughs)
M3: so I mean it was crazy
PI: yeah wow, thank you for going back and sharing a little bit more about that I really appreciate it. Um, so you were just saying a little bit ago that your baby got sick and that's when you had to go to the special care nursery, so um, tell me a little bit about what happened with that.
M3: um yeah so the baby started, you know he started feeling, to this day he still is being fed with a g-tube
PI: ok

M3: so um, with back then in January of last year he wasn't feeling really good he was feeling, he wasn't keeping his feedings down, so um, we had took him in and they're like he has um, I'm not sure, I'm not sure I think it was January. He had gotten sick and he was there for maybe a week I think about week or maybe a week and a half that time. But he had gotten sick and I don't remember what it's called, like he got sick and he was born with a spleen
PI: ok
M3: so without a spleen, without a spleen he can get any kind of infection
PI: right
M3: the second he has a small infection um he has a hospitalization so I was like oh my gosh we're gonna go through a lot with this little guy
PI: yeah
M3: so just, every, once he starts spitting up his fluids, I mean his feedings, is when he I know he's not feeling good so, so we had to come in and I think he has had light bonsitis or something like that, he was being treated for then. He had to have oxygen use
PI: OK
M3: and then he had to do the breathing treatments with the, what is that thing called, the nebulizer.
PI: oh yeah ok
M3: yeah and then just for him being there that time they wanted him to do like little stretches and physical therapy and stuff like that so um and then um it was just a lot there that day, that I had to take on for him because he is born really small
PI: right
M3: to this day his fontanel is still really large, it didn't close.
PI: ok
M3: um, his kidneys are at a smaller size and I think it was the left side at the last MRI they did not see any functioning in that side of the kidneys
PI: OK
M3: so he does have a lot of doctors to see with everything (laughs)
Pi: yeah I'm sure
M3: so we were there I think about a week and a half there with him
PI: OK
M3: um and this will be, I think it was almost like almost like going through the same thing every day, for him, um, but, he finally got to go home within a week on oxygen so, knowing that he had to go home on oxygen and having to carry another bag with me it was like his feeding back and then having to carry another oxygen bag with me just to take him home (laughs)
PI: yeah (laughs)
M3: and I was like ok
PI: oh wow
M3: um yeah and then he was home maybe January, February, and then march was when we noticed that he wasn't holding down his feedings again like in march
PI: yeah
M3: and I was like ok he's burping up a lot and dad got scared cause dad was like, dad was like this type of vomit, this type of __ at the same time, that's what baby was doing here at home and baby was like a blueish color and dad was like we need to take him in, something is going on
PI: yeah
M3: so we had taken him in to the flagstaff emergency we just thought you know, um, feeding him for a couple of hours, they did x-rays on his stomach and they're like um we see something going on with his intestines again so from there they had to fly him out to banner

PI: oh wow
M3: to the same doctor that had done his malrotation
Pi: yeah
M3; um so he got flown out to banner hospital that evening and me and dad just come back home and we packed some clothes and we took off down to banner we were at banner for like a week that time and that time he had um a closed loop, closed loop bowel obstruction
PI: oh ok
M3: um so he was there for like a week and a half, maybe two weeks back then?
Pi: wow
M3: maybe yeah because yeah, and it was bad and I was like oh my gosh this is gonna take a, we're gonna be here for a while again and its gonna be a long road again and I'm in the hospital with him again and just like unexpected. Just have days where you're like oh we gotta go do this and we just gotta deal with it some way somehow, ugh, so, I was down there with him in march for his bowel obstruction surgery and after he came back, they had got him back up to the room he was, he was doing ok, and then I think a day after surgery he just, like his whole body he just got like so swollen and all of his toes his fingers his hands
PI: yeah
M3: his face, you know just looking at his eyes and he could barely open his eyes
PI: poor thing
M3: just the feeling of his hands felt like once you like hold it or once you barely raise it or it feels like his hand is gonna pop or something that's how swollen he was.
PI: yeah
M3: and there was then when he was there and trying to hold him, I was scared to hold him with everything like so, so, swollen like that
Pi: right
M3: um, I feel like its good for him to you know change positions of laying down because the more you move the more his body will lessen the swelling and the swelling will start to go down and once they had told me that I was like oh ok and that's when they started offering you wanna hold him and I was like yeah ok well if this will help the swelling go down well yeah I will hold him (laughs)
PI: right yeah
M3: (laughs) so I was really glad to start holding him and within like 4-5 days the swelling was like completely gone
PI: oh good yeah
M3: yeah, so we did really good with, he felt really good after, and we had come back home, and then let me see like, in the summer he did ok, like summer seasons he does ok, it's just um, recently like October the 21st he was hospitalized again here at flagstaff.
PI: oh ok
M3: but it wasn't at the special care nursery it was at the pediatric side
Pi: yeah
M3: so, that was everything in October, and I think he was there for about 4 or 5 days, and then we got to go home exactly on Halloween day (laughs) so that I was really happy to be home on Halloween because when he was born we were in the hospital for Halloween, thanksgiving, and Christmas, so um, to be let go from the flagstaff hospital on Halloween I was like super excited for him (laughs)
PI: (laughs)
M3: even though were in this pandemic I was we can stay home and have fun as long as we can be home on Halloween (laughs)

PI; Right! Oh my goodness. And so, I want you to go back to that week you spent at the special care nursery um you told me a lot about your experiences, was there anything difficult during that week while you were there or anything memorable about your stay there?
M3: um, um, I guess that, I think the only thing that kept me really calm staying there and being there with him was that time, dad could stay there with me.
PI: yeah
M3: the dad could stay there with me and I really felt glad that he was there with me because if I was there by myself I would be like so stressed out so worried about everything
PI: yeah
M3: but I'm so glad they had let dad stay there with me
PI: yeah me too
M3: to come and help because they're like if he cries during the night you know and we tried to calm him down and he's not calming down, we're gonna call one of you guys to the room you know just that in that sense of like ok I'm not going to be the only one staying up at night.
PI: yeah
M3: even though we're in the hospital with him
Pi: right
M3: Um I think that was, that really was good for me and for dad because it taught dad like patience, like, being in the hospital you've got to have patience with everything that goes on and everything, I think he really understood being there and just having patience for everything
PI: yeah
M3: but it does give you some time, like why does my child have to go through this, and you know just questions that you have on your own that happen in your own mind I guess
PI: yeah absolutely, yeah. Tell me about your experiences with the special care nursery staff during your week there.
M3: um, they, the week we were there they, I think they handled everything pretty well I mean they did everything really good, they handled everything good, its just, I think him noticing that you know mom and dad are not sometimes would kinda upset him and he would cry. They would call us and say you know I think he wants you guys here or he wants to hear you guys' voice. They were really good about that and so.
PI: that's great
M3: that was really helpful and I think just the times I start to feel like I want to go hold him or something is when he would start crying
Pi: yeah
M3: and that's when they would call and say you know he's crying you guys want to come in and talk to him and hold him, but they were really good on doing their part and taking care of him and we could hold him and they would tell us was really good. I really appreciate their time and their efforts and helping us in that way.
PI: that's great, that's really good. And tell me about your experiences with visiting and caring for your baby at the special care nursery you know where did you stay when you were there and were there any financial burdens or how did you get there back and forth, tell me a little bit about that.
M3: um, we did get to stay there where the special care nursery is and just on the side of the building they have like the um little rooms where I guess parents can stay so. For a couple of nights me and dad stayed in the room which is just outside the two double doors from the special care nursery, just on the other side they had room so, we got to stay in there for about two maybe three days, three nights, and they weren't giving us a discharge date so they were

thinking we would be there a little bit longer so um we can get you guys into the Taylor house, which is just like across the street from the hospital.
PI: yeah
M3: so I'm really glad they go to do that because I mean, sometimes just being in the hospital can get frustrating somethings and just having to stay across just across the street it was really good too
PI; right
M3: and then they did call us from there that baby is feeling a bit and he wants to see you guys and they would still call us from there and it was still really good that we got to stay just across the street in the Taylor house
PI: yeah, that's so nice
M3: so I mean financially they didn't ask um for any you know to stay there they didn't ask for money or anything or any cards to stay there so that was really helpful. The only thing we had to buy mainly for ourselves was like food wise
PI: yeah
M3; um, but the Taylor house if we wanted to cook anything or make anything we had to buy it with our own money, but um it wasn't, it was just me and dad and with just the being there and worrying so much you really don't feel hungry at all (laughs)
PI: (laughs) yeah
M3: so, it was really good. It was really good though.
PI: that's good yeah. Any other thoughts you want to share about your overall experience caring for your baby at the special care nursery?
M3: Um, I would say it is a lot to go through, um, it's a lot to take in sometimes and sometimes you just really feel like breaking down and crying and while you're holding your baby and sometimes I did do that (laughs)
PI: yeah I'm sure
M3: you know, holding your baby and crying and saying I'm sorry I don't know what happened and yeah. It's just a lot to go through, but I'm glad they were there to help us through that and if I needed anybody to talk to they would say we have a counselor here you can talk to but I was in that sense I was so glad dad was here with me this time instead of being all the way down at Banner by myself
PI: yeah
M3: which is pretty nice that dad got to stay there with me and help me through that and, it was really comforting and, I was just so glad to have him there. But at the special care nursery they did a good job of taking my baby and helping him get better so. And they did keep me updated on everything that was going on with him so. They did a really good job.
Pi: yeah, that is so good to hear. And it sounds like your husband is such a strong source of support for you, I'm so glad he was able to be there.
M3: yeah
PI: so, this is actually my last question for you, and were getting closer o 5 so were making perfect time, but I just want you to tell me some good thing you hope for or wish for your baby in the future.
M3: I wish him the very best (laughs) I really do wish him the very best, he's my baby boy he's so precious to me, um, I really hope that you know he stays healthy and continues to get stronger, um, learn new things, um right now he is about a month and a half, almost two months in sitting up on his own, so that's one huge step for him. We just can't wait to really hear him talk I mean right now it's just dada mama, no, and he really understands so we know his doing ok, um, it's just him getting stronger, um and crawling and standing and he continues to get really strong

each and every day. And I pray and I hope that he does he is gonna be healthy and he'll be ok and that I really don't have to spend so much time at the hospital with him any more (laughs) um, but me and his dad will always be there with him when he gets sick or when he doesn't feel good we'll always be there with him. So I'm really glad I got to go through this with his dad.
PI: I'm sure
M3: and I just with my baby boy the very best of being healthy and staying strong
Pi: yeah
M3: well gosh this has been such an incredible story to hear, you're an amazing mom and it sounds like baby has an amazing dad and you have so much support and I just really appreciate you sharing this with me today. It sounds like you've gone through so much with this baby, tough things and good things and um, yeah so thank you so much for sharing this with me I really appreciate it.
M3: ok then.
PI: do you have any questions or want to add anything else before I end the recording
M3: um I just want other mothers out there that go through this and just let them know to be strong, stay strong and be there for your baby um it's gonna be tough but hang in there (laughs) and I would just like to say thank you
PI: well thank you. That is such an awesome thing to end on. Your story is going to help a lot I think. I really, really, appreciate it.

Appendix G: Analytic memo writing for each interview

Diana’s Interview:

Comments I made through journaling and when listening to audio:

- Mom seemed apprehensive to talk about difficulty, but then would say it is difficult
- Mom expressed a lot of fear
- This pregnancy seemed really hard and complicated
- COVID impacted her pregnancy
- Despite a complicated pregnancy, mom felt comfortable in the NICU with staff
- Culture is important to her
- Mom had very positive NICU experiences, especially loved nurses in NICU
- Mom wanted to share her experience, very open to sharing
- I felt nervous to ask her about the blood transfusion

Cori’s Interview:

Comments I made through journaling and reading her interview:

- This mother has been through a lot, I know she also lost her grandfather to COVID on top of all of these things happening.
- Her pregnancy was surprising to her but she was immediately ready, as she had already been a mom to her little girl
- She needed her family during the NICU stay, but they came through in different ways

Renee’s Interview:

Comments I made through journaling and when listening to audio:

- This mother told her story with humor and emotion
- This mother’s birth experience didn’t match her plan and she was feeling surprised and upset
- She had such an awesome and supportive partner
- She benefits a lot from family and advice from family and friends
- This mother was amazingly open and vulnerable about all pieces of her NICU to home experience